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ABSTRACT

The third of six volumes on deinstitutionalization of mentally retarded persons provides case study descriptions of the deinstitutionalization process of 10 selected institutions. The information is said to have been gathered from results of questionnaires and family interviews. The bulk of the document is devoted to detailed case studies with information on the following topics: state's and institution's deinstitutionalization policies, client assessment procedures, pre-release programs, release procedures, followup and support services, profiles of released clients, and profiles of re-admitted clients. (CL)

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Contract No. OEC-0-74-9183

# CASE STUDIES OF THE DEINSTITUTIONALIZATION PROCEDURES OF TEN SELECTED INSTITUTIONS SERVING MENTALLY RETARDED PEOPLE

September, 1976

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Volume III of

A Study of the Community Adjustment
of Deinstitutionalized Mentally Retarded Persons

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# ACKNOWLEDGEMENTS

In July, 1974, Abt Associates was awarded a contract by the Bureau of Education for the Handicapped of the United States Office of Education to conduct an assessment of the adjustment of deinstitutionalized mentally retarded people to community life (Contract No. OEC-0-74-9183). The present volume is one of a six-volume series produced over the course of the project to describe deinstitutionalization procedures of institutions and community adjustment experiences of mentally retarded persons. We are deeply indebted to many people for their cooperation and assistance in all phases of this project.

First, we wish to give special thanks to our Project Officer in the United States Office of Education's Bureau of Education for the Handicapped, William Johnston, for providing support and guidance to us throughout the course of the contract, and to Max Mueller, Chief, Research Division, BEH.

The Abt Associates research staff who assisted in this project worked long and difficult hours to prepare, analyze, and report the data in these volumes. First, we wish to thank Patricia Cook, who served as the Project Director of this study from July, 1974 to May, 1975. Special thanks go to Diane Stoner, Supervisor of Field Operations, and to Jaime Grubin and coders from the Survey Design Group for pre-coding our instruments and subsequently coding the data; to Joe Clark, Sandy Friedman, and Paul Robertson for their invaluable help in preparing the complex data base and carrying out the computer work; to Jim Hoell and Karen Schneiderman for helping organize the data into meaningful tables and charts; and to Kathy Moss and Paul Robertson for assistance in writing up our findings.

We are especially grateful to Professor Norman R. Kurtz of the Florence Heller School for Advanced Studies in Social Welfare, who served as an on-going consultant on this project. He was helpful in various phases of the project, particularly in reviewing our instruments, developing and carrying out our analysis plan, and reviewing our working documents.

Corporate staff at Abt Associates who deserve thanks for their support and guidance are Andy Anderson, our contract management reviewer, and Peter Miller, Education Area Manager and Vice-President.

The study involved two major field efforts: 1) visits and interviews by field staff at 10 selected institutions serving mentally retarded persons; and 2) visits and interviews by field staff with the 440 deinstitutionalized clients and their families. The field staff worked enthusiastically and effectively in collecting the data, sometimes under difficult field conditions and time constraints. We wish to thank the field staff who conducted the site visits to the ten institutions--Marjorie Scarlett, Laurie Stewart, and Bonnie Wilpon--as well as the staff who conducted interviews with deinstitutionalized clients and their families--Sharon Alperin, Joel Braun, Amy Cicala, Michael Clifford, Barbara Epstein, Eleanor Franklin, Lois Gerardi, Ellen Hartford, Lauri Lewis, Vicki Peters, John Schlichte, Suzanne Simenson, and Jan Valley.

Special thanks go to the Mohawks and Squaws, a consultant group of mentally retarded persons, and to Adrienne Glenn in particular, who helped sensitize and train our field staff to the process of interviewing mentally retarded persons. We are also grateful to the institutions and persons who assisted us in pre-testing instruments and questionnaires--particularly the staff at Monson State School, Monson, Massachusetts, and the staff at Seaside Regional Center, Waterford, Connecticut, and the host of families, group home staff, and deinstitutionalized clients.

We wish to thank the 154 institutions which responded to our initial mail survey and particularly the staff at the 10 institutions participating in this study. Participation required a great deal of time and effort on their part, with little promise of returns which could directly benefit them. Their motivation for participating was based on a desire to assist in a research project which they felt was greatly needed. We hope that our study reports meet their expectations and will be helpful in preparing training programs and placing clients in community settings. The institutions participating were:

Arlington Developmental Center
Arlington, Tennessee

Beatrice State Home
Beatrice, Nebraska

Belchertown State School
Belchertown, Massachusetts

Brainerd State Hospital
Brainerd, Minnesota

Brandon Training School
Brandon, Vermont

Northern Wisconsin Colony and Training School
Chippewa Falls, Wisconsin

Polk State School and Hospital
Polk, Pennsylvania

Suffolk Developmental Center
Suffolk, New York

Sunland at Tallahassee
Tallahassee, Florida

Utah State Training School
American Fork, Utah

Above all, our praise and thanks go to the 440 deinstitutionalized clients and their families who participated in this study. They spent long hours with our interviewers providing difficult information on community adjustment experiences. As with the participating institutions, there were no direct benefits to them for participating in the study. Without their efforts and insights a report such as this could not have been written. We can only hope that the findings and recommendations of this study might facilitate the community adjustment of persons who are released from institutions in the future.

Elinor Gollay, Project Director
Ruth Freedman, Deputy Project Director
Marty Wyngaarden, Research Analyst

PREFACE: PROJECT OVERVIEW

Objectives

This report is based on a study conducted by Abt Associates Inc. for the Bureau of Education for the Handicapped of the United States Office of Education (Contract No. OEC-0-74-9183). The overall purpose is to assess the adjustment of deinstitutionalized mentally retarded people to community life. The objectives are six-fold:

1. to review the criterion measures and predictors of community adjustment used in studies of mentally retarded persons and to analyze the research issues related to these projects. The findings of this review are contained in Volume I: Approaches to Defining and Measuring the Community Adjustment of Mentally Retarded Persons--A Review of the Literature.
2. to describe the current patterns of deinstitutionalization based on a mail survey of 250 institutions across the nation involved in deinstitutionalizing mentally retarded persons. Volume II: Profile of National Deinstitutionalization Patterns 1972-1974 summarizes the findings of this survey.
3. to describe the deinstitutionalization procedures and policies of 10 selected residential institutions serving mentally retarded persons based on field visits made to these facilities by project staff. The findings of these visits are published in Volume III: Case Studies of the Deinstitutionalization Procedures of Ten Selected Institutions Serving Mentally Retarded People.
4. to describe the community experiences of mentally retarded persons, based on interviews with 440 clients (released from the selected institutions described in objective 3) and their "families" (e.g., parents, foster parents, guardians, or whoever was providing care and supervision for the client in the community setting). This descriptive data is presented in Volume IV: Descriptive Data on the Community Experiences of Mentally Retarded Persons.
5. to determine what institutional, client, and community factors contribute to successful community adjustment based on the interviews described in objective 4 and on institutional data collected during the field visits to the ten institutions. Volume V: An Analysis of Factors Contributing to Community Adjustment presents the findings of this analysis.
6. to summarize the findings of the previous 5 volumes and to provide recommendations to USOE for further research related to deinstitutionalization based on the analysis of the data collected according to the objectives described above. These findings are published in Volume VI: Executive Summary--Overall Findings and Recommendations.

## Overall Research Design

The overall research design employed in this study is depicted graphically in Table A. As can be seen from the table, there were four major phases to the study design: 1) conceptualization; 2) instrument design; 3) data collection; and 4) analysis and report writing. The findings reported in Volumes 1-6 were based upon the procedures undertaken in each of the four phases. In order to present an overall picture of the research design, the phases will be briefly described in this section. More detailed information on these phases as they relate to each of the specific volumes is presented in the "Methodology" section of each individual volume.

## Conceptualization

The first major phase involved developing a conceptual model of deinstitutionalization and the community adjustment process. First, a review of the literature was conducted. Based on the findings of this review (reported in Volume I), a model was developed setting forth the study's assumptions about the process of deinstitutionalization and community adjustment. The model included nine sets of variables which encompassed the major characteristics of deinstitutionalization and the community adjustment experiences. The nine sets of variables are listed at the bottom of Table A (see "a" in Table A). More specific information on the content of these variables and their role as independent and dependent measures is contained in the "Methodology" section of each individual volume.

## Instrument Design

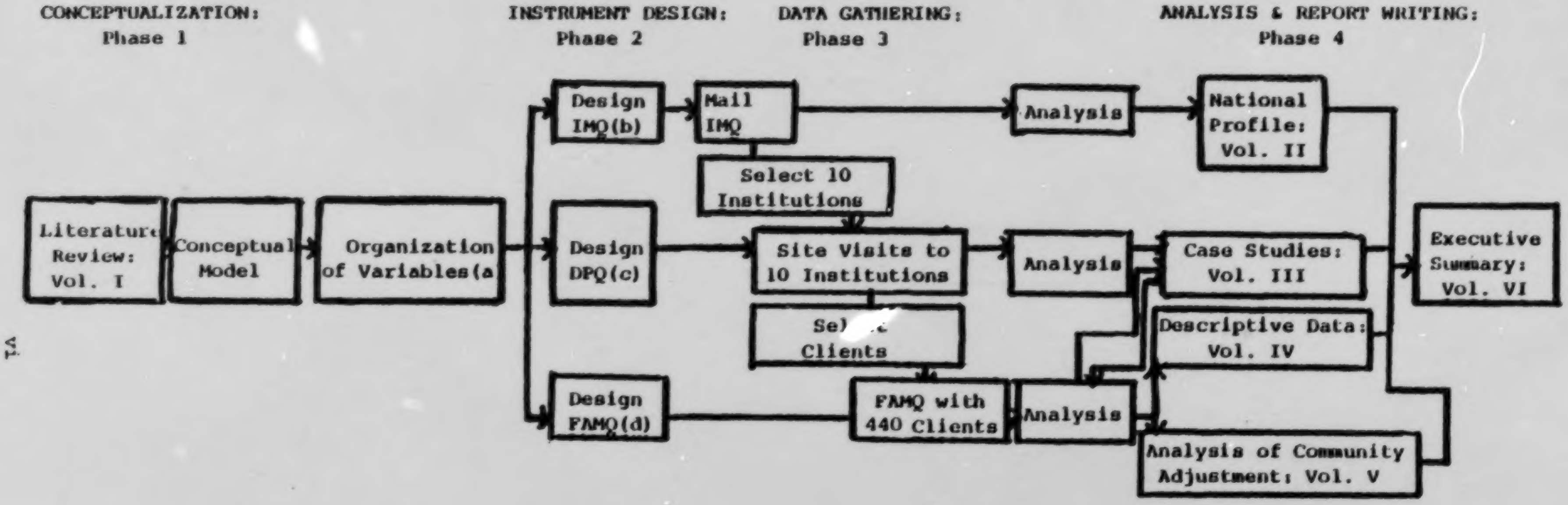
Three groups of instruments were designed to collect data on the nine variable sets:

1. Institutional Mail Questionnaire (IMQ) — a mail questionnaire designed to obtain information on the deinstitutionalization procedures and release patterns of 250 institutions across the nation serving mentally retarded clients.

2. Deinstitutionalization Procedures Questionnaire (DPQ) — a questionnaire designed to survey ten institutions selected for in-depth case study descriptions regarding deinstitutionalization and pre-release policies, procedures and programs.

## TABLE A.

## OVERALL RESEARCH DESIGN.


CONCEPTUALIZATION: Phase 1
INSTRUMENT DESIGN: Phase 2
DATA GATHERING: Phase 3
ANALYSIS & REPORT WRITING: Phase 4
Literature Review: Vol. I
Conceptual Model
Organization of Variables(a)
Design IMQ(b)
Design DPQ(c)
Design FAMQ(d)
Mail IMQ
Select 10 Institutions
Site Visits to 10 Institutions
Select Clients
FAMQ with 440 Clients
Analysis
Analysis
Analysis
National Profile: Vol. II
Case Studies: Vol. III
Descriptive Data: Vol. IV
Analysis of Community Adjustment: Vol. V
Executive Summary: Vol. VI

(a) Sets of Variables

- Client Characteristics
- Institutional Characteristics
- Community Characteristics
- Residential Characteristics
- Day Activity Experiences
- Residential Experiences
- Services and Training
- Social & Civic Activities
- Problems & Interpersonal Relationships

(b) IMQ Data Areas

- Residential Population
- Release Patterns
- Pre-Release/Post-Release Services
- Institutional Clearance Procedures for Study

(c) DPQ Data Areas

- State Policies/Legislation
- Client Assessment Procedures
- Pre-Release Programs
- Release Procedures
- Follow-Up Procedures and Support

(d) FAMQ Data Areas

- Interview with Client
- Interview with Family
- Adaptive Behavior Scale
- Client Data Recording Form
- Final Comments Sheet

3. "Family" Questionnaires (FAMQ) -- a series of instruments designed to obtain data on the community adjustment experiences of deinstitutionalized clients living in the community. The types of instruments included in the Family Questionnaire are listed at the bottom of Table A (see d in Table A). The instruments included an interview questionnaire to be administered to the deinstitutionalized client; a questionnaire administered to the client's family; an Adaptive Behavior Checklist (ABS) measuring the functional level of the client; a Client Data Recording Form (CDRF) obtaining demographic data from institutional records about the client (e.g., age, number of years institutionalized, date of discharge, etc.); and a Final Comments Sheet (FCS) to record the interviewer's impressions.

## Data Gathering

The three sets of instruments described above were administered to the appropriate respondents in a sequential fashion. First, the IMQ was mailed to 250 institutions serving persons across the nation. Ten institutions were selected for in-depth case study descriptions (see "Methodology" sections of volumes for description of selection procedures used for IMQ respondents). The 10 institutions were then visited by project staff to collect data using the DPQ. Based on the data and on further contact with institutional staff, 440 deinstitutionalized clients released from their institutions were selected for study. (See "Methodology" section of volumes for descriptions of these selection procedures.) Finally, the FAMQ series of instruments was used to gather data on study group clients.

## Analysis and Report Writing

The data described above were analyzed and reported in several ways. The findings based on IMQ data are reported in Volume II: Profile of National Deinstitutionalization Patterns, 1972-1974. The data obtained from the DPQ was analyzed in two ways: 1) case study descriptions of the individual institutions and a cross-case study summary which is reported in Volume III: Case Studies of the Deinstitutionalization Procedures of Ten Selected Institutions Serving Mentally Retarded People; and 2) portions of the DPQ data served as independent variables for the analysis reported in Volume V: An Analysis of Factors Contributing to Community Adjustment. Similarly, the FAMQ data were analyzed in several ways: 1) data on the community experience of clients in the study group are reported descriptively in Volume IV: Descriptive Data on the Community Experiences of Mentally

Retarded Persons and also in the final chapter of each institution's case study description in Volume III; 2) FAMQ data are organized into independent and dependent measures of community adjustment and reported in Volume V: An Analysis of Factors Contributing to Community Adjustment. All of the data collected and reported in Volumes 1-5 were then analyzed in terms of their implications for overall study findings and recommendations. These overall findings and recommendations are reported in Volume VI: Executive Summary.

## Organization of the Volume

This volume provides case study descriptions of the deinstitutionalization procedures of the 10 selected institutions. Section 1.0 serves as the "Methodology" chapter, describing the various steps taken to design, collect, and analyze the data. Section 2.0 is a cross-case study summary which compares the major characteristics, programs, and policies across the ten institutions. Sections 3.0 - 12.0 present individual case study descriptions of the ten institutions. The final section is a Glossary which defines the major terms used in this study (such as "target client," "deinstitutionalization," etc.).

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* Dover State School is a fictionalized name for this facility, used at the request of the participating institution.

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[*] Hudson State School is a fictionalized name for this facility, used at the request of the participating institution.

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* The Yorktown State School is a fictionalized name for this facility, used at the request of the participating institution.

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GLOSSARY

# 1.0 INTRODUCTION: METHODOLOGY

## 1.1 Conceptualization

### 1.1.1 Introduction

A conceptual model for assessing the community adjustment of deinstitutionalized clients was developed through a lengthy process. First, the literature was reviewed for previous work in this area. (See Volume I for the findings of this review.) Persons currently conducting similar research were contacted by telephone or in person and asked to describe their projects. Materials obtained from these sources were then reviewed for relevance to this study.

Based on the above steps and on the practical experience and knowledge of Abt staff and consultants about the deinstitutionalization process, staff identified the major research question of this study:

> What are the major institutional, community, and client variables which contribute to the successful adjustment of deinstitutionalized mentally retarded people to community life?

A conceptual model of community adjustment was then developed to address the research question stated above. The purpose of the model was to set forth the study's assumptions about the process of deinstitutionalization and community adjustment, and to help organize the sets of dependent and independent variables around which the instrument design, data collection, and data analysis were organized.

### 1.1.2 Study's Assumptions Regarding Deinstitutionalization and Community Adjustment

One of the major findings of the literature review was that the terms "deinstitutionalization" and "community adjustment" have been widely used, connoting different meanings and values in various contexts. It was therefore essential to clarify the meanings of these terms and their use in the study's conceptual model.

Deinstitutionalization has traditionally referred to the preparation for and release of institutionalized persons into community settings. For the purposes of this study, deinstitutionalization is defined as the placement of mentally retarded people in community settings following their enrollment in residential institutions (facilities serving over 100 handicapped clients) for two or more consecutive years. "Community placements" or settings include natural homes, foster homes, group homes, and semi-independent as well as independent living units. In this study, community placements did not include residential settings which were restrictive or as sheltered as the institutions from which clients were released (e.g., nursing homes, state schools, and state hospitals), nor residential settings serving over 100 persons. In order for a mentally retarded person to be considered deinstitutionalized, s/he must have resided in the community (i.e., sleep in and have as a mailing address the community residence), but may have received some day or support services at the institution from which s/he was released.

Community adjustment is defined in this study as an interactive process in which an individual adapts over time to the community environments in which s/he lives (e.g., adaptation to work, school, residence, etc.). The time and budget constraints of this study, however, limited the extent to which this adjustment process could be measured:

(1) Adjustment could not be measured across two or more time periods--rather, data was collected only at one point in time.

(2) The study focused almost exclusively on the adaptive behaviors of the individuals to the various contexts and settings in which they live, and did not attempt to examine these settings' adaptation to the demands and needs of the individual.

### 1.1.3 Organization of Variables

A list of variables related to deinstitutionalization and the community adjustment process was generated by project staff, based on the major research question and theoretical assumptions of the study. Variables were organized into two major sets: (1) dependent variables, or measures of the outcome of community adjustment; and (2) independent variables, or predictors of community adjustment. The sets of independent variables deal with client characteristics and experience prior to release into community settings, and dependent variables describe clients' community experiences and adjustment since release into the community. The relationships among and between these sets of variables are the focus of this study's analysis.

Specifically, three subsets of independent variables are analyzed in terms of their relationships to four subsets of dependent variables.

The independent variables include the following subsets:

(1) Subject Variables--characteristics of the deinstitutionalized mentally retarded persons (e.g., age, sex, intelligence level, functional level);

(2) Community Variables--characteristics of the community settings in which clients are placed (e.g., type and size of setting, proximity to shopping and transportation services); and

(3) Institutional Variables--characteristics of the institution itself (e.g., size, per capita expenditures, staff/client ratios) and of the clients' former institutional experiences (e.g., training received while at institution; work, school, and social activities while at the institution).

The major dependent variables are organized into four subsets:

(1) Day/Residential Experiences--data related to clients' experiences in day and residential placements in the community (e.g., type of placement(s), client satisfaction with placement(s));

(2) Services and Training--data on types and frequency of services and training received by clients (and families) since client's release from institution;

(3) Social and Civic Activities--data on types of activities and frequency of participation by clients since release from the institution (e.g., leisure activities, friendships); and

(4) Problems and Interpersonal Relationships--data on client and family perceptions of the client's management of interpersonal relationships with day activity participants and staff and community residents in general; and on types of problems encountered by clients and families.

### 1.1.4 Limitations

A major limitation in developing the conceptual model was the limited amount of previous theoretical and empirical work done in this area. The literature review indicated that little data exists on community adjustment of deinstitutionalized persons, and few, if any, relationships have been established between measures of community adjustment and the deinstitutionalization process. In developing the conceptual model and the specific variables, therefore, there was little to draw upon from previous research. Because a body of knowledge has not yet been established in this area, it is very possible that some important variables may have been overlooked.

The variables selected cover a broad range of issues related to the deinstitutionalization process and community adjustment experiences. Certain types of variables, however, were excluded:

(1) Variables too difficult to collect, given the cost and scope of the contract. For example, variables potentially related to community adjustment, such as the self-esteem of deinstitutionalized clients or the community acceptance of released clients, are extremely difficult to measure. The time required to develop data in these areas was simply beyond the scope and intent of the study.

(2) Variables too sensitive to include in interviews: Certain areas of adjustment, such as sexual and legal problems of clients, were considered too sensitive in nature, and potentially offensive to clients, to be included in in-depth interview questionnaires.

(3) Variables not relevant to the basic focus of the study: The assessment of adjustment through focus on the activities of the clients limited the collection of data in other equally interesting areas. For example, detailed data on the nature of the groups homes to which residents were released, although equally interesting, was not identified as primary for this study.

## 1.2 Instrument Design

### 1.2.1 Design of the Institutional Mail Questionnaire (IMQ)

A questionnaire was designed and mailed to approximately 250 institutions identified by the National Center for Health Statistics as serving mentally retarded clients. The instrument was brief, to encourage responses. Its purposes were twofold:

(1) To provide data on institutions which would enable the project staff to select 10 institutions for participation in the main study of community adjustment of deinstitutionalized mentally retarded persons; and

(2) To provide data for developing a national "profile" of deinstitutionalization patterns. The profile would be used for two purposes: first, it would stand on its own as a report on these patterns; second, it would provide a base for comparison of the information gathered on the ten institutions used in the deinstitutionalization study.

Data were gathered on the following topics: number of clients served by the facility; number released to various types of community settings;

age and level of retardation of clients placed in various community settings; types of pre-release services and post-release services available; and institutional approval procedures required to contact clients about the study.

### Limitations of the IMQ

Definitions for some key terms in the Institutional Mail Questionnaire may not have been adequately operationalized. Specifically, no definition was provided for the term "releases." This was an unfortunate oversight. The term "releases" was intended to include both formal discharges and extended visits where the resident lives in the community for an indefinite period of time but is still on the institutional rolls. Undoubtedly, some institutions might have interpreted the term "releases" to mean only formal discharges. To the extent this is true, the numbers reported are biased in favor of more mildly retarded older persons who are more likely to be formally discharged than younger, more severely retarded persons. On the other hand, some institutions might have included short-term visits such as a month's visit to parents, and thus introduced the opposite bias. It is, therefore, difficult to estimate the type of bias resulting from any misunderstandings of this term.

Moreover, no operational definitions were given for types of community placements listed in the questionnaire. An effort was made to choose widely-used terms, but again, their use and meaning varies. Thus, in some states, the term "group home" has a very specific meaning, whereas in others it can include situations in which there are four to fifty residents. This probably did not create too much difficulty, however, as evidenced by the fact that a relatively small proportion of releases were to "other settings" and that a clear definition was provided for "community settings" in general.

### 1.2.2 Design of the Deinstitutionalization Procedures Questionnaire (DPQ)

The Deinstitutionalization Procedures Questionnaire (DPQ) was developed by project staff to collect information on two major sets of variables: (1) those necessary to produce descriptive case studies on the deinstitutionalization policies and procedures of the 10 facilities; and (2) those necessary to analyze factors contributing to successful community adjustment. A description of the major variables selected for inclusion in this instrument and the rationale for their selection follows:

- Presence of State and Institutional Deinstitutionalization Policies. It was felt that the presence of a formal policy setting forth specific goals related to deinstitutionalization might effect the institutions' placement procedures and the subsequent community adjustment of former residents.

- Presence of State Right to Education Law. A Right to Education Law, if implemented, is likely to improve the range and quality of educational services available to mentally retarded persons both within institutions and within communities. As a result, it might be expected that the presence of such a law would simultaneously improve the preparation and training received by a mentally retarded person while institutionalized, and improve the range and quality of educational services available to that person in the community. Since release from an institution is usually based on a combination of factors including both the readiness of the individual for entering the community and the ability of the community to find reasonable residential and day placements for the individual, it would seem that a strong right to education law would be an important factor to consider when examining deinstitutionalization.

- Presence of Periodic Review Law. Of primary importance for this study was the assumption that, through periodic reviews of institutionalized mentally retarded persons, those people considered to be ready for community placement would be identified; and those who lacked specific community readiness skills would also be identified and provided with the necessary training.

- State Litigation Related to Deinstitutionalization. Class actions and individual litigations concerning mentally retarded persons were investigated for their potential impacts on the institutions' deinstitutionalization policies and procedures. For example, many states' institutions have been involved in right-to-treatment suits in which the quality of institutional programs and facilities have been challenged. The settlement of these court suits has often resulted in additional funds to improve physical conditions, upgrade staffing levels, and increase the number and quality of programs designed to prepare residents for community living.

- Client Assessment Procedures. Institutions vary in the procedures they use to assess and review the needs and progress of residents while living in the institution. The procedures vary in scope (e.g., psychological, educational, social, or vocational assessments), in frequency, and in the types of staff involved. It was assumed that assessments which were comprehensive in scope, frequent, and interdisciplinary might result in more accurate identification of residents' readiness, their needs regarding community living, and more appropriate placements.

- Pre-Release Programs. The types of programs which institutions may develop to prepare clients for placement into community settings include residential and work/school programs both at the institution and in the community. This study was concerned with the range of different types of pre-release programs and preparation provided residents, as well as the specific characteristics in terms of types of training provided. Since the extent and quality of the pre-release training received by a mentally retarded person prior to release into the community is potentially an important factor affecting eventual adjustment, it was important to obtain detailed information on these programs.

- Release Procedures. The types of procedures and criteria involved in releasing residents from institution to community settings vary greatly, and are likely to influence who gets released to which settings. Therefore, the perceptions of institutional staff regarding the major factors affecting the release process were of interest--e.g., their view of the importance of the functional level of the client, parental attitudes/desires, availability of employment opportunities in the community, and existence of local/county support services.

- Follow-Up Procedures and Support. The nature and source of on-going support and responsibility for care of mentally retarded people living in the community can be expected to affect adjustment. In some states, the institution has primary continuing responsibility for residents after their release to community settings. In these cases, the institution is responsible for maintaining contact with former residents and for providing assistance and services necessary to facilitate their adjustment. In other states, a county or regional welfare or mental health office may assume these responsibilities, or may share them with the institution. This study examined the different arrangements in order to determine their impact on community adjustment.

The majority of the questions in the DPQ were close-ended to facilitate coding and use of the variables in the analysis of community adjustment. Open-ended questions were reserved for variables used only in the case study descriptions. The questionnaire was pre-tested at institutions for the mentally retarded in two states to refine the questions, estimate the time involved in conducting interviews, and to determine appropriate respondents. The questionnaire was then revised on the basis of these pre-tests.

### Limitations of the DPQ

A major limitation of the DPQ was that it provided data on deinstitutionalization only from the institutions' perspective. No information was obtained on the views of such significant others as community representatives, consumers, or state officials. In addition, the DPQ dealt only with institutional characteristics presumed to relate directly to deinstitutionalization; thus, no general overview of the characteristics of the institutions can be provided.

### 1.2.3 Design of the Family Questionnaire (FAMQ)

Variations in the types of settings of clients and their families necessitated the design and use of nine specific questionnaires. In each case, the family of the client was interviewed first.* The client was interviewed separately if able to participate.

Table 1 describes the types of instruments administered and the primary respondents in each setting. As shown in the table, two instruments were used to gather information on deinstitutionalized clients and their families. For example, for clients living in foster homes, two questionnaires were administered--the Foster Parent Questionnaire to the foster parents, and the Resident Questionnaire to the client. By administering two questionnaires in the case of each deinstitutionalized client, the perspective of both the client and his/her "family" were obtained.

Table 2 specifies the types of data collected in each of the nine instruments. As can be seen, the data gathered in all of the questionnaires (except the Resident Questionnaire) were quite similar; they differed only in certain questions specific to the particular setting. For example, in the Natural Parent Questionnaire, certain questions were asked about parent and sibling relationships with the client, whereas in the Housemanager's Questionnaire, questions were asked about the client's relationship with staff and the overall staffing patterns in the group home.

In addition to the questionnaires, the following instruments were also used to gather information about each client:

(1) Adaptive Behavior Scale (American Association on Mental Deficiency): Administered to the family or contact person about the client's current level of functioning in a variety of domains (e.g., social, vocational, physical, personal). This standardized scale has been used in many related studies in this field. (Referred to as ABS)

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* "Families" is used here to refer to the deinstitutionalized client's natural parent or parents; foster parent(s) or guardian(s); group home housemanager(s); or any other person(s) who provide care and supervision to the client in the community setting. In cases where deinstitutionalized persons were living independently, a contact person from the community (such as the client's social worker) was interviewed as well.

Table 1.

Types of Questionnaires and Respondents for Each Community Setting

| Setting in Which Client Lives: | Types of Questionnaires To be Administered: | Types of Respondents: |
|---|---|---|
| Clients in Natural/ Adoptive Homes | (NQ) Natural Parent Questionnaire | Natural/Adoptive Parents |
| | (RQ) Resident Questionnaire | Client |
| Clients in Foster Homes | (FQ) Foster Parent Quest're | Foster Parents |
| | (RQ) Resident Questionnaire | Client |
| Clients in Group Homes | (HQ) Housemanager Quest're | Housemanager/House Staff in Group Home |
| | (RQ) Resident Questionnaire | Client |
| Clients in Semi-Independent Settings | (SILQ) Semi-Independent Setting Questionnaire | Staff persons working directly w/client in setting (e.g., social workers, rehabilitation counselor) |
| | (RQ) Resident Questionnaire | Client |
| Clients in Independent Settings | (ILQ) Independent Living Questionnaire | Client |
| | (ILQ-C) ILQ-Contact Questionnaire | Person in close contact w/client (e.g., social worker, landlord, employer, etc.) |
| Clients who have Returned to the Institution | (NQ, FQ, HQ, SILQ, or ILQ-C) * | Contact person who knew most about client when s/he lived in community |
| | (REQ) Returnee Quest're | Returned client |

* In interviewing the returnee contact person, the questionnaire appropriate to the setting in which the client lived while in the community was used. (Questions were phrased in the past tense for the contact person.)

Table 2.

Type of Data to be Collected in Each Instrument

| Instrument | Data to be Collected |
|---|---|
| (1) Resident Questionnaire: | Client satisfaction with residence; clients' satisfaction with day placement (e.g., work, school, etc.); major problems since leaving institution; skills learned in institution to prepare resident for living in the community; skills which could have been taught at institution to prepare resident for community living; skills acquired by resident since living in the community; skills which resident wants to learn in the community. |
| (2) Returnee Questionnaire: | Information about when client lived in the community; paralleling Resident Questionnaire data. |
| (3) Natural Parent Questionnaire: | Background information on resident's relationship to and contact with the client; background information on the client; skills learned in the institution; skills needed by client for living in the community; services used and/or needed by the client and respondent in the community; client's day placement (e.g., school, work, etc.); client's spare time activities; client's socialization in the community; client's community adjustment. |
| (4) Foster Parent Questionnaire: | (Same as information listed for "Natural Parent Questionnaire") |
| (5) Housemanager's Questionnaire: | (Same as information listed for "Natural Parent Questionnaire") |
| (6) Semi-Independent Living Questionnaire: | (Same as information listed for "Natural Parent Questionnaire") |
| (7) Independent Living Questionnaire: | Background information on client; client's day placement (e.g., school, work, etc.); services used and/or needed by client in the community; client's satisfaction with residence; client's satisfaction with day placement; skills needed to be learned to live in the community; skills learned at the institution. |
| (8) Questionnaire for Contact Person of Resident in Independent Living Setting: | Background information on respondent's relationship to and contact with the client; respondent's perception of client's community adjustment; skills client learned in the institution; skills client needs to learn to live in the community. |

(2) Final Comments Sheet (FCS): A series of observational scales and impressionistic data filled out by the interviewer after the interview has been completed. The FCS includes data on the interviewer's impressions of the client's adjustment, satisfaction, and social integration; the client's overall appearance (demeanor, cleanliness, dress); the physical condition of the client's home and setting; as well as information on the conduct of the interview itself.

(3) Client Data Recording Form (CDRF): Demographic information about the client gathered for this study by the institutions from their records. CDRF data included: age, sex, race, level of retardation, number and length of institutionalizations, commitment and discharge status, participation in pre-release programs.

- Limitations of the FAMQ

The major limitation encountered in designing these instruments was the fact that little research has been done in this area. Very few studies have attempted systematic data collection with this population group; therefore, few sophisticated scales exist which could be incorporated into the design of these instruments.

In addition, very little is known about the most effective structuring of questions to be used in interviewing mentally retarded clients. The FAMQ relied mostly on closed-ended questions which may have suffered from a narrow perception of what the possible responses were. Open-ended questions were used occasionally in questionnaires administered to clients when the range of possible responses was unknown or unpredictable. These open-ended questions, however, may have erred in the opposite direction of the close-ended ones; that is, the potential range of responses to these questions ran the risk of being too broad to aggregate and code.

## 1.3 Study Group Selection

### 1.3.1 Selection of Respondents for IMQ

A directory was obtained from the National Center on Health Statistics which provided a list of 250 institutions nationally serving mentally retarded persons. The Institutional Mail Questionnaire was mailed to these institutions in the fall of 1974; one hundred fifty-four institutions responded.

### 1.3.2 Selection of Ten Institutions for DPQ

Of those institutions responding to the Institutional Mail Questionnaire, 26 were identified which met the following four screening criteria:

(1) The institution must be residential and serve at least 100 clients. Rationale: The cutoff point of a minimum of 100 clients was selected to correspond with the definition of "institution" used in this study (see Glossary).

(2) The institution must have deinstitutionalized (i.e., released to community settings) at least 50 mentally retarded clients between the ages of 6 and 40 who had been enrolled in the institution for two or more years prior to release, since January 1, 1972. Rationale: In order to arrive at a sample of approximately 500 deinstitutionalized clients, it was imperative that each of the 10 institutions selected had released at least 50 clients. The reasons for including clients within a certain age range and with certain institutional characteristics are given in the section which describes procedures for selecting clients.

(3) The institution must maintain a list of current addresses or telephone numbers of its deinstitutionalized clients. Rationale: Since the study's procedures for obtaining a sample of deinstitutionalized clients was dependent on the accuracy of the institutions' files on released clients, only institutions which claimed that they had current addresses and telephone numbers of released clients were included.

(4) The clearance procedures for obtaining consent for the institution to participate and to contact deinstitutionalized clients could not exceed 4 - 6 weeks. Rationale: Each institution indicated through the mail survey the specific clearance procedures necessary for them to participate (e.g., review and approval of institutional officials, state officials, human rights commissions, etc.). Because of the time constraints of this project, only those institutions which anticipated clearance procedures within boundaries reasonable to the project (i.e., less than 4 - 6 weeks) were included in the institutional study group.

Of the pool of 26 institutions meeting the above criteria, 10 were selected using the following guidelines:

(1) At least 5 states should be represented. It was felt that the 10 institutions should be geographically diverse.

(2) A wide range of deinstitutionalization processes should be represented, so that the case studies could be as varied and informative as possible.

(3) States with different types of Right to Education Laws should be represented, since this may be an important potential variable in the deinstitutionalization experience of clients.

(4) The institution had to be willing to participate. The study was voluntary, and could obviously include only those institutions which consented to participate.

### Limitations of the Selection Process on the Data

Three basic limitations are imposed on the data by the process for selecting the ten institutions. First, the initial group of institutions which responded to the mail survey is a self-selected sample. It is impossible to determine whether the institutions which responded differed from non-respondents, since no data on non-respondents was available.

Second, the four screening criteria used to limit the pool of appropriate institutions to 26 further restricted the types of institutions included. They had to be relatively large, have released a fairly large number of clients to community settings, had to have records on the whereabouts of their released clients, and had to have relatively easy clearance procedures. These institutions and the clients released from their programs may well differ from the institutions eliminated during the screening process.

Third, the selection of the final 10 institutions was dependent on the willingness of institutions to participate. Two of the ten initally selected refused to participate, and had to be replaced by other institutions from the pool of 26. One of the institutions refused because of concern about the amount of work involved in participation; another because of recent major administrative staff changes at the institution. It may be that the institutions consenting to participate differed from those which refused. Generalizability of the study findings must be viewed cautiously because of these limitations imposed by the selection procedures. No definitive statements can be made regarding the representativeness of the 10 institutions to the total universe of similar institutions serving mentally retarded clients. However, there is no reason to assume that the ten institutions are unique. A detailed description of the institutions is available in Volume III.

### 1.3.3 Selection of Deinstitutionalized Clients for FAMQ

The sampling pool for selecting deinstitutionalized clients from these ten institutions was based on four basic criteria:

Criterion 1: Clients had to have lived in the institution for two or more years.

Rationale: This requirement was seen as important to control for the confounding effect that relatively brief institutional stays would have on assessing community adjustment.

Criterion 2: Only clients were included who were released from the institution to a community placement.

Rationale: Since the goal of this study was to assess the community adjustment of persons released from institutions, a definition of community was developed. In this study, community placements referred to natural homes, foster homes, group homes, semi-independent and independent living settings (see Glossary for definitions of these specific types of settings). The definition excluded as community placements residential settings which were as large, restrictive, or sheltered as the institution from which the clients were released. Excluded from the definition were placements in state schools and hospitals, nursing homes, residential settings serving over 100 persons.

Criterion 3: Only clients between the ages of 6 and 40 years at the time of release were accepted.

Rationale: The age range of 6 - 40 years was selected in agreement with the Bureau of Education for the Handicapped. While some children under the age of 6 may meet the criterion of two years of institutional experience prior to community placement, the number would have been too small to be analytically useful for this study. Persons over the age of 40 were excluded because many in this age group are deinstitutionalized to nursing or convalescent care settings which did not meet the study's definition of community placement.

Criterion 4: Clients were included only if they were released from the institution between January 1, 1972 and December 31, 1974. Rationale: The time period for releases was arrived at in consultation with the Bureau of Education for the Handicapped. Projections indicated that a 3-year period would be necessary to obtain a sample of 500 released clients. A person was considered "released" if s/he resided in the community (i.e., slept in and had as a mailing address the community residence), and if s/he was explicitly considered to to living either permanently or on a trial basis outside the institution.

Clients meeting all of these criteria constituted the study group pool and are referred to throughout this volume as "target clients." Occasionally, reference is made in the case studies to non-target clients--those released from the institutions who did not meet the criteria specified for inclusion in this study. The distinction made between target and non-target clients is solely a function of this study, and does not indicate a distinction made by institutions or institutional personnel.

## Confidentiality and Consent

In order to ensure that the privacy of all deinstitutionalized clients was protected, participating institutions agreed to make initial contacts with clients in the sampling pool. Abt Associates developed a standard letter describing the study, detailing what participation would involve on the part of the client and his/her family, and requesting that they sign and return an enclosed consent form agreeing to participate.

The consent form, developed by a legal consultant experienced in this field, was written in a style which could be understood by a mentally retarded person and/or the client's family. Clients signing the form gave consent to participate in the study, and have basic information about them gathered from the institution (e.g., age, level of retardation, number of years institutionalized, etc.). Legal consent was furnished by the parent or guardian if the client was a minor or judged legally incompetent. If the client was neither a minor nor judged incompetent, the client was required to sign the consent agreement.

The consent forms were sent to the 10 institutions which took responsibility for mailing them to eligible deinstitutionalized clients. Clients and their families were instructed to return the signed consent form directly to Abt Associates if they were interested in participating in the study. In this way, Abt Associates did not make any direct contract with the client and his/her family until after they agreed to participate; and researchers never learned the names of clients who declined participation. Thus, the confidentiality and privacy of both the respondents and non-respondents were ensured.

## Response Rate of Sample

One thousand two hundred and forty-two target clients (1,142) were released from the participating institutions. Of these target clients, 919 were living in the community and 323 had subsequently returned to the institution (i.e., were released and who satisfied our selection critieria during the 1972-1974 period, but who since returned to the institution). Of the 919 non-returnees contacted in the first mailing, only 296 agreed to participate. Therefore, a second mailing was conducted. This procedure yielded an additional 101 non-returnees, thereby increasing the total response from both mailings to 397 non-returnees or 43% of the total 919 non-returnee sample.

It was decided that the study should also interview a sample of the 323 returnees. It was felt that the inclusion of returnees could provide valuable information on a subset of persons who failed to adjust to the community on at least one criterion--remaining in the community. Eight-three (83) returnees agreed to take part or 26% of the total returnee sample.

Ninety-five (95) envelopes never reached the intended clients because of faulty addresses, and in addition, three persons who responded were eliminated from the sampling pool because they did not actually meet the selection criteria (e.g., they were really in nursing homes or they had never in fact been released from the institution). Thus, the total number actually contacted in the first mailing was 1,144 target clients (i.e., 1,242 minus 95).

The total response sample was 480 persons (397 living in the community and 83 returnees) constituting 42% of the 1,144 people actually contacted. It should be noted , however, that the final sample size decreased slightly by unavoidable contingencies in the field, such as clients deciding at the last minute that they did not want to participate, and the presence of conflicting vacation schedules. In sum, the 440 final study members constituted 35% of the 1,242 target group members identified by the institutions.

## Limitations of Final Sample Selection Procedures on the Data

Several aspects of the selection process limit the generalizability of the data obtained from the final sample of deinstitutionalized clients. First, the selection criteria and definition of "target" clients were in some ways arbitrary. We could have, for example, used a one-year residence requirement in the institution and/or we could have included a wider (or narrower) age range. There is, of course, no way of knowing the effect of the selection criteria on the composition of the sample and the ensuing results.

Second, the procedure was voluntary. It is impossible to determine whether the persons consenting to participate differed from the non-respondents since no information was obtained about persons who did not respond or who decided not to participate.

Third, it is possible that the final sample is biased toward persons who did not frequently change residence after release. Letters sent by the institutions to clients requesting their participation never reached 79 clients because their addresses had changed or were incorrect. It is difficult to know whether these persons differed from the final sample of clients.

Finally, the sample may underrepresent clients placed in certain types of settings and overrepresent clients from other types of settings. For example, it is possible that proportionately more clients from group homes and natural homes elected to participate because they were living with or supervised by persons who could assist and encourage them to respond to the request. On the other hand, persons living in independent settings may be underrepresented because there was no one in their immediate setting who could assist or encourage them to respond.

While little can be done about the possible limits introduced by client selection procedures, an attempt will be made in other data presentations to provide descriptions of the clients in great enough detail to permit the reader to pass judgement on the types of clients included in the study.

## 1.4 Data Gathering

### 1.4.1 IMQ Data Gathering

The Institutional Mail Questionnaire was mailed in the fall of 1974 to 250 institutions across the country serving mentally retarded persons. A follow-up mailing took place in December, 1974. Virtually all institutions not responding were telephoned during January and February, 1975 to encourage them to respond and to find out why they had not. Through these data collection efforts, 154 institutions responded to the IMQ.

### 1.4.2 DPQ Data Gathering

Each of the 10 institutions participating in the study were visited by research teams. The objectives of these site visits were threefold:

(1) To gather data necessary to produce descriptive case studies on the deinstitutionalization procedures and policies of these facilities;

(2) To gather data on characteristics of the institution identified as possible independent variables in the proposed analysis plan for factors contributing to successful community adjustment; and

(3) To review with the institutional staff the proposed procedures for contacting the deinstitutionalized clients and for gathering information about them from the institutions' case records.

Four interviewers from Abt Associates experienced in interviewing staff in programs for the mentally retarded visited and administered the DPQ at the 10 sites. The DPQ respondents varied at each site; in most cases, the superintendent of the institution participated, as well as other staff having knowledge of the items covered in the questionnaire. For example, the Director of Social Services or Community Placement, where such positions existed, responded to items in that area. Interviewers were instructed to record the responses of the institutional staff to each questionnaire item in an effort to collect information which could later be reported in a descriptive case study. It generally took six to eight hours to gather the information for the DPQ and to review the proposed procedures for contacting the clients

### Limitations of the Data Collection Effort on the Data

There are several limitations imposed by the data collection efforts described above:

(1) The role of the case studies was primarily descriptive and not evaluative. Moreover, the interviewers merely recorded this information provided by institutional staff, and no effort was made to verify the accuracy of the information due to time and budget constraints. Thus, the reliability and accuracy of the ensuing data might be questioned.

(2) Although the questionnaire and data requirements of the DPQ were mailed to each institution in advance of the actual site visit, many institutions had difficulty in providing demographic data about the institutions. Often, they felt their records were inaccurate or not updated. In cases where they could not provide exact figures, they were asked to provide their best estimates.

(3) The DPQ was administered at each site to only a small number of respondents, usually the superintendent of the institution and from one to three other key staff persons. Therefore, the data collected is limited in its perspective. No attempt was made to interview all

of the institutional staff or to obtain a representative view of the deinstitutionalization policies and procedures at the facilities.

(4) The DPQ was administered in a short period of time--interviewers generally spent 6 to 8 hours collecting the data for the DPQ. Because of the site visit schedule and the limited descriptive (as opposed to evaluative) role of the case studies, interviewers had little opportunity to observe programs at the institutions or to talk to staff other than the specific DPQ respondents. However, later, in the summer months when the interviews with deinstitutionalized clients took place, many of the field interviewers visited the institutions to observe the pre-release and residential programs in which the clients had participated. In some cases, their observations and information about the institutions were then incorporated into the appropriate case studies.

### 1.4.3 FAMQ Data Gathering

#### Field Staff Selection and Training

A total of 14 field staff were hired by Abt Associates to conduct the interviews and gather the data. Two types of field staff were recruited: field interviewers, who were responsible for conducting the interviews with deinstitutionalized clients and their families; and field supervisors, who, in addition to conducting interviews, were also responsible for making the initial contacts with clients and their families; for setting up the entire schedule of interviews for their site; and for supervising the work of field interviewers on their team. The field staff, recruited from universities, school systems, and programs and facilities serving mentally retarded persons, included special education teachers, rehabilitation counselors, group home staff, psychologists, and staff from state institutions for the mentally retarded.

All field staff underwent four days of intensive training. During the initial training sessions, they were introduced to the project and given an orientation to each of the data collection instruments. A training manual outlining all field procedures was provided to each staff member to be utilized on-site. Subsequent training sessions included: an introduction to general interviewing practices; specific instructions for administering each of the instruments to be used in the study; questions and answers about the study which might arise in the field; potential problems in the field and suggested solutions; and item specifications clarifying the intent of each question in each of the instruments.

Role-playing techniques were utilized in the training sessions to give field staff practice in conducting and recording interviews. In addition, a housemanager of a group residence for mentally retarded persons and a mentally retarded client living independently in the community served as sample respondents. Each of the field staff had an opportunity to interview these persons. In order to further orient the staff to the sensitive process of interviewing mentally retarded persons and their families, the Mohawks, a Massachusetts-based group of mentally retarded adults who present training and sensitivity sessions to professionals, met with the field staff to give them feedback on the problems of living in the community and of being interviewed in studies such as the Abt project.

### Field Effort

A field staff team was stationed at each of the 10 sites to conduct interviews with clients and their families. In most cases, the team consisted of one field supervisor and one field interviewer. In a few cases, however, the teams were larger because of the number of respondents in that site or because of the distances involved in travelling to respondents' homes. In one case, because of the small number of clients involved, one field supervisor conducted all of the interviews for that area.

The overall field effort was supervised and coordinated by an Abt Associates field coordinator. All field supervisors were required to report to the field coordinator daily while in the field, to discuss the field team's work, problems, and questions.

The interview appointments for field staff were arranged before the actual site visit by the field supervisor of the team. The schedule was arranged to minimize travel time. Thus, a field staff member would conduct the interviews of all clients living in a particular town before travelling on to another area in the site.

Clients were given the choice of being interviewed in their homes, at the institution, at the Abt staff person's hotel, or any other place they requested. Almost all of the interviews were conducted in their homes or at the institution (mostly in the case of returnees). Some clients requested and were interviewed at their place of work so as not to inconvenience their work schedules.

The interviews were conducted during July, August, September, and October of 1975. On the average, field staff members conducted two Family Interviews and two Resident Interviews a day, although this varied depending on the location and type of setting involved. For example, in a group home setting, the field staff member might, in one day, conduct interviews with the housemanager about three clients and then interview each of these three clients individually. This was possible because all of the clients were in one setting and the housemanager served as the respondent for all of these cases. In another case, however, it might have been possible to conduct only one Family and one Resident Interview on a given day if the client was living with his natural family in a rural setting which required 2½ hours of travel time.

Generally, a Family Interview (i.e., using the Natural Parent Questionnaire, the Foster Parent Questionnaire, the Housemanager or Semi-Independent Questionnaire) or an interview with an independently living client (using the Independent Living Questionnaire) took 2 to 3 hours. The interview with the contact person of the independently living client usually took one to 1½ hours; the Resident Questionnaire was completed in about 45 minutes.

After the field effort was completed, a half-day de-briefing meeting was conducted at Abt Associates in order to get feedback from the field staff on their work. At this meeting, overall impressions of the field effort were discussed as well as specific feedback, criticisms, and suggestions regarding particular items on each of the questionnaires.

In general, the field staff felt that they were well received at the sites. The clients, their families, and any staff who participated (at the request of the clients or families) were most cooperative. Although the interview sessions were quite long, the respondents seemed eager to provide field staff with the necessary information. Often, they viewed the interview as an opportunity to vent their feelings and give "their side of the story."

### Limitations of Field Procedures on Data

The main limitations of the data imposed by the field procedures used in this study are described below:

(1) The data was collected during the summer months and early fall. This particular period of time was selected

to meet contract deadlines and to attract competent interviewers who might be more available during this time (e.g., special education teachers, graduate students, etc.). However, certain clients may have been unable to participate in the study because of conflicts in schedule such as vacations. Every attempt was made to schedule appointments at the client's convenience. In fact, in many cases, interviewers returned to certain geographic areas to interview those persons who were excluded in the first wave of interviews because they were unavailable. However, a small number of persons whose schedules could not be accommodated were not included in the study.

(2) In collecting the data, no attempt was made to verify the accuracy of the information provided by the respondents. The perceptions of the respondents were taken at face value. In cases where two respondents in an interview provided discrepant information, they were contacted to "adjust" the discrepancies. If both parties insisted that their information was accurate, two varying responses were recorded.

(3) It was difficult to control for the fact that some respondents may have answered questions too positively; that is, they may have overstated how well they were doing in the community in order to please the interviewer or out of fear that information about their adjustment would be fed back to the institution. Every effort was made to reassure respondents about the confidentiality of the information and the importance of responding as honestly as possible. However, there still may have been some respondents who felt compelled, for whatever reason, to respond less than accurately.

## 1.5 Data Analysis and Reporting

Once the site visit was conducted, the interviewer was responsible for writing a case study on the institution, according to a standard outline developed by project staff. The case study, about 20 pages long, summarized the data collected on all of the topics described in Section 1.3. These case studies were then reviewed by an in-house editor for substance and stylistic consistency. After this editing process, each institution was sent a draft of its case study for review and comment. Their suggestions were then incorporated into the final case study reports.

At the time that the draft case studies were sent to the institutions, a Supplemental Questionnaire was also sent to them, which contained additional

## 2.0 CROSS-CASE STUDY SUMMARY

### 2.1 Introduction

The purpose of this summary is to describe the major characteristics, programs, and policies of the ten institutions, based on the data presented in the individual case studies. This is not intended to serve as a statistical analysis of the data; rather, the summary will describe narratively the deinstitutionalization trends present at these ten institutions, highlighting major differences and similarities wherever possible. The summary will be presented according to the organizational format of the individual case studies with the following sections:

2.2 Overview
2.3 State Context
2.4 Client Assessment Procedures
2.5 Pre-Release Programs
2.6 Release Procedures
2.7 Follow-Up and Support Services
2.8 Released Client Profile
2.9 Profile of Re-Admitted Clients
2.10 Summary

### 2.2 Overview

All ten institutions were public facilities serving mentally retarded children and adults. With the exception of one institution, the facilities served only persons whose primary handicapping condition was mental retardation; the exception to this policy served, in addition, mentally ill and chemically dependent persons. Three institutions were responsible for serving residents from throughout the state; the other institutions were one of several within their state and therefore served a particular geographic region within their state.

The mean residential population of these facilities in the Spring of 1975 was 965, with a range from 360 to 2,300 residents. Most of the institutions (eight of the ten) experienced declining residential populations during the 1972 - 1975 period. The percent decrease among the institutions ranged from 7% to 30%. Two institutions experienced population increases over the 1972 - 1975 period--one increased by 7% and the other by 9%.

every two years or as needed. The assessments cited by institutions as being most frequently conducted were in the medical and educational areas.

Interdisciplinary staff teams, including physicians, nurses, social workers, psychologists, educators, and others, were involved in these client assessments, according to all of the institutions. In four of the institutions, families, guardians, or advocates of residents were generally invited to participate in these assessments. Less than half of the families invited ever participated, according to staff. In seven of the ten institutions, staff reported that residents often participated in these assessments, mostly by reviewing and discussing the assessment findings with staff. Other persons or agencies from outside the institution (e.g., rehabilitation agencies, consultants) were invited to participate in the assessments conducted at nine of the ten institutions.

## 2.5 Pre-Release Programs

At nine of the ten institutions, there were three to six pre-release programs designed to prepare residents for placement into community settings. (The remaining institution reported that it did not have specific pre-release programs for groups of residents; that instead, all programming was individualized.) Of the 38 pre-release programs across the institutions, 19 consisted of separate residential dormitories or wards designed to prepare clients for community living, 15 of which were vocational or pre-vocational programs (the majority being sheltered workshops on the grounds of the institution), and four of which were pre-release school programs located in communities near the institutions.

Major strengths of the pre-release programs most frequently cited by staff at the institutions were individualized programming for residents and the presence of positive, dedicated staff. The most commonly cited weaknesses of the pre-release programs as perceived by staff were lack of community resources and involvement, lack of skilled staff, lack of funds and other resources at the institutions.

## 2.6 Release Procedures

The release procedures which typically occur prior to a resident's release from an institution were quite similar across all of the institutions studied. Generally, interdisciplinary teams periodically review each resident's readiness for community placement. When a resident is considered ready for placement, the resident, parents, schools and/or community agencies are contacted for their input regarding available and appropriate placements. Once a placement is identified, the resident visits the setting on trial basis (ranging from one day to three weeks). If the trial visit(s) are successful, the resident is then released by the institution to that setting, usually on an "extended visit" or temporary basis as opposed to being formally discharged from the institution.

In most of the institutions, the large majority of residents were released primarily because of the institution's initiative (i.e., institutional staff felt that the resident was ready for release), as opposed to family initiative (i.e., the family requested that the resident be released). At all of the institutions, a resident released on an extended visit or temporary basis has the right to return voluntarily to the institution without regard to any waiting lists or waiting periods. This right is generally revoked once a resident is formally discharged. In half of the institutions, the superintendent or director did not have the legal power to return a released resident to the institution involuntarily. In the remaining five institutions, the superintendent could do so, but only through a court order and/or with court-committed cases.

According to staff at the institutions, the criteria most frequently used to determine whether a client is ready to be placed in the community are: functional level of the client; availability of residential placement in the community; and, availability of day program alternatives in the community. There were striking similarities in the descriptions provided by staff at the ten institutions of the characteristics of clients considered easiest and most difficult to place in the community. Clients easiest to place were described in the following manner by staff at most of the institutions: good self-help, social, interpersonal, and communication skills; few or no medical problems; few or no behavioral problems; and normal appearance. Similarly, clients considered most difficult to place were most frequently described as: lacking self-help skills; having medical or ambulation problems or other handicapping conditions requiring a high degree of care; behavior/emotional problems; and abnormal appearance.

## 2.7 Follow-Up and Support Services

Follow-up contact, or efforts to keep track of where former residents are living, and how well they are doing in their placements, was considered the sole responsibility of the institution at three of the facilities. At four institutions, this responsibility was shared jointly by institutional and regional staff; in three cases, follow-up contact was not at all the responsibility of the institution, but rather was undertaken by the county or regional offices of mental retardation or welfare. Generally, institutions reported that released residents were followed up monthly. Sometimes, the frequency of follow-up was dependent upon the type of setting in which the resident lived--in two institutions, follow-up was much more frequent for residents in group homes than for those persons living with their natural families.

Similarly, with follow-up support services, the institution's responsibility for providing such services varied at the different facilities. In most cases, the institutions shared this responsibility with regional, county or community agencies; in most cases, institutions were responsible for providing support services only to clients released on an extended visit or temporary basis. The types of support services most frequently cited as being provided to released residents were social and medical services. Other supports included educational, vocational, recreational, and psychological services.

In most cases, support and/or training provided by the institution to families or caretakers of residents and/or employers/teachers of residents were limited or nonexistent. When such support was provided, it generally consisted of training in behavior modification techniques and individual counselling to families and caretakers, consultations and workshops for employers and teachers.

None of the institutions formally evaluated how well released clients were adjusting to life in the community, but most institutions informally assessed the adjustment of clients through discussions with staff, families, employers/teachers and through case reviews and reports. Most institutions felt that the majority of their released clients were adjusting extremely or very well. Similarly, it was felt that only a small percentage of clients were adjusting fairly or poorly (estimates of the percentage of clients in these categories ranged from 10% to 20%). The types of clients making an excellent adjustment to life in the community were most frequently described by staff at the various institutions as having: high functioning ability, lack of conflict in residence and day program, good motivation, good social and interpersonal behaviors, and general acceptance by the community. The following characteristics were most frequently used to describe those clients adjusting poorly to community life: behavior/emotional problems, medical problems, poor interpersonal/social relationships, and low motivation.

### 2.8 Profile of Released Clients and Re-Admitted Clients

This section presents some of the characteristics of the total released populations at the institutions (i.e., target clients plus non-target clients released during the 1972-75 period).* The percent of the total institutional population released into community and/or non-community settings varied greatly across the institutions, with ranges from 3% to 24% of the total institutional population. Most often, released clients were mildly or moderately retarded adults.

The types of settings to which clients were released varied tremendously across the institutions. In general, more clients were released to natural homes and group homes than to foster homes, independent settings, or other institutional settings. However, the percentage of clients released to the different types of settings varied so much across institutions that no definite trends in placements can be identified.

The percent of target clients re-admitted to the institutions varied greatly, ranging from 1% to 50%. The majority of the re-admitted clients were adults who had remained in the community for six months or less. The settings from which these clients most frequently returned were natural families and group homes. The reasons most frequently cited by institutions for these re-admissions were: behavior problems or medical problems of the client; breakdown or closing of the client's "family" placement settting.

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* See Glossary for definitions of target and non-target clients.

## 2.9 Summary

Striking similarities across the ten institutions were revealed in the case study descriptions. Almost all of the institutions had experienced similar population trends, such as reductions in residential populations and increases in the proportions of severely and profoundly retarded residents. Deinstitutionalization policies, legislation, and litigation were present at all of the institutions. Client assessment procedures and release procedures were quite similar across the institutions. Although the number of pre-release programs varied at each institution, the types and ranges of programs did not differ in any substantial ways. Similarly, with follow-up services, the sources of follow-up varied somewhat, but the types of services and frequency of provision remained quite consistent. One of the most striking similarities revealed in the case study descriptions was the perceptions of staff regarding characteristics of residents easiest and most difficult to place in the community, and of residents making excellent and poor community adjustments. The descriptors used by staff to characterize these residents were consistent across almost all of the institutions.

The presence of these similarities, however, does not imply that there was no variation among the ten institutions. Although programmatically the institutions appeared quite similar, some demographic characteristics of the institutions did vary. For example, there was great variation across the ten sites in the percent of institutional residents released during the 1972-1974 period, the percent of residents released to the various types of community settings, and in the percent of clients re-admitted to the institutions.

# CHAPTER 3.0: ARLINGTON DEVELOPMENTAL CENTER

## 1.0 INTRODUCTION

### 1.1 Overview

Arlington Developmental Center is a residential institution located on a 604 acre site near a suburb of Memphis, Tennessee. Opened in 1969, Arlington is the newest of Tennessee's three centers for the developmentally disabled. The Center, which is under the jurisdiction of the State Department of Mental Health, serves residents of 21 counties in the western third of the state. Persons are admitted to Arlington on a "time-limited" basis, meaning that the Center tries in every possible case to release residents after a two-year stay; this is, however, not possible in all instances. The Center promotes the philosophy that it is a community program and only a part of the umbrella of services for the mentally retarded. The staff at the Center state that the primary goal for its clients is normalization, or the desire to create an environment within the institution which most closely reflects the life style of the comunity. Because of its committment to place as many residents as possible into community settings the Center tries to establish programs and policies which facilitate the development of community-living skills.

Many former residents of Arlington Developmental Center are now involved in one of 38 small special-purpose programs in the area, most of which are privately operated and serve mentally retarded people. These programs include sheltered workshops, infant stimulation programs, day-training centers, adult activity centers and group homes. It is hoped that several more group homes or residences will be opened within the next several years.

Arlington's overall population has shown little variation in size during recent years. Between 1972 and 1974, there was no change in the population of 561 clients. From 1974 to 1975, however, a slight 3% reduction was noted, to 542 clients. The residents have been consistently 46% female for these years.

The population currently residing at Arlington Developmental Center varies significantly in two respects from the population living in the Center during the period under study. First, the age range has shifted towards a more even distribution between children and youth (ages 6 through

18 years) and adults (ages 18 and over). In 1972, 62% of the population was under 18 years of age. By 1975, 49% were in this range. Secondly, the current levels of retardation among the institutional population show that despite the fact the majority of those released during the 1972-1974 period were either severely or profoundly retarded (see Section 6.0), 86% of the current population is classified in these two categories. In fact, Arlington has had, since 1972, its most sizable population in the severely and profoundly retarded classifications. Mildly retarded residents accounted for 8% of the 1972-1974 population and 6% of the 1975 population. Moderately retarded clients, 12% of the population during the period under study, currently constitute 8% of the population.

The incidence of other handicapping conditions in addition to mental retardation has not varied since 1972. The most common additional handicaps were mobility problems (approximately 70%), epilepsy (approximately 46%), and psychiatric problems (approximately 36%).

Over 90% of Arlington's residents are admitted to the center by parental or guardian authorization. Staff report that it is a standard procedure at the Center to have each new resident's parent or guardian sign an authorization form for voluntary admission for the resident.

## 1.2 State Context

### 1.2.1. State's and Institution's Deinstitutionalization Policies

The state has no formal legislation or regulations relating to the deinstitutionalization of retarded persons. Since 1973, however, the State Department of Mental Health has adopted administrative policies in this area. According to these policies, persons are admitted to one of the three state institutions on a time-limited basis with specific goals for their treatment; they are not admitted unless the institution can provide appropriate programming for them. Further, the state Department of Mental Health has stated that community-oriented services are a priority within its operations. Community services are provided by a division within each of the three state Centers, in cooperation with the regional office of the State Department of Mental Health serving a Center's cathcment area. (The regional office is officially located within the institution's Community Services Division). The Community Services Division within each

Center thus serves as the hub of services for all mentally retarded residents of the area, particularly those in the area's institution. The Community Services Division works with the regional office to develop specific programs for each resident so that, upon release, the resident will be able to be placed in the type of community program most appropriate for him/her.

Arlington's policy, which has been in operation since it opened, essentially consists of providing care, treatment, and training and carrying on research, as well as developing community programs for the mentally retarded. However, because of the fact that release into the community depends largely on the availability of appropriate settings, the institution sets no yearly goals for the number of percent of clients to be deinstitutionalized.

## 1.3 State Legislation Relating to Deinstitutionalization

### 1.3.1. The Right to Education Law and Its Impacts

The state's Right to Education law was passed in 1972. According to this law, "It is the policy of this state to provide, and to require school districts to provide, as an integral part of free public education, special education services sufficient to meet the needs and maximize the capabilities of handicapped children." The law applies to children between the ages of 4 and 21 years, with all types of handicapping conditions, at all levels of severity. In essence, the law removes the responsibility for education of mentally retarded children from the Department of Mental Health, and places it in the hands of the State Department of Education. Other provisions of the law include the creation of an advisory Council for Education of the Handicapped, a Special Education Services Association, requirements for the Commissioner of Education to make plans for the implementation of special education, etc. According to the Director of Community Services, one of the law's eventual results will probably be the concentration of more of Arlington's resources on its adult population, given that children will be better cared for by Department of Education resources.

A three-year period was provided for implementation of the legislation; 1972-73 was a planning year. By the fall of 1974, all previously verified handicapped children had to be enrolled in a school program.

However, 1974-75 was also somewhat of a "grace period," since it was provided that school systems could use this time to identify and test all unverified handicapped children, and to develop a plan of services for them. By 1975, full implementation was to have occurred, with all newly verified children enrolled in a school program in the fall of that year. According to Arlington staff, these phases have so far been completed on schedule.

According to the Director of Community Services at Arlington, the Right to Education law has, to some degree, increased the number of clients placed in their natural homes, since some families will take their children home if there is a day program available for them in the community. As has been stated previously, this legislation has also resulted in Arlington's placing more priority on its adult population, given that the education of mentally retarded (and other handicapped) children is now the legal responsibility of the Department of Education. Also, as an indirect result of this legislation, the Center has taken steps to aid in the establishment of a group home for children during the next year. The home, which was due to be opened in the spring of 1975, will eventually increase the number of children who may be placed in the community by the Center.

### 1.3.2 The Periodic Review Law and Its Impacts

The state has enacted no periodic review legislation. However, Arlington has had a periodic review policy since 1971. This policy states that all residents of the institution must be reviewed by an interdisciplinary team at least annually. The purpose of the annual review is to set up programs for each individual resident. In addition, residents' programs are to be reviewed quarterly to determine their appropriateness, and the residents' progress within them. Parents are invited to the annual review, and if they do not attend, a social worker from the institution contacts them to inform them of the results of the review. This institutional policy is currently in a partial stage of implementation. By the end of 1975, the staff hope that the policy will be modified to provide for monthly rather than quarterly program reviews.

The periodic review policy at the institution has had a number of impacts on the operations at Arlington. According to the Director of Community Services, this policy has increased the number of clients served by educational and pre-release programs at Arlington by around 50%. In addition, it has increased the quality of these programs by bringing about more individualized and more objective (as opposed to subjective) programming. Some 30% of the clients at Arlington are now participating in off campus trips as well. The Director of Community Services also feels that the periodic review policy has increased the number of clients placed in their natural homes, because it has persuaded social workers to become more active in encouraging families to take children back into the home.

When the periodic review procedure identified people who were potentially able to live in group homes in the community, the institution began to push for the establishment of such homes. (There was only one group home in the western part of the state in 1971). As a result of Arlington's efforts in this context, a new group home was opened in 1972. Thus the policy has had an indirect effect in the placement of clients in group homes. It has had a similar effect in relation to the establishment of semi-independent programs in the community. Such a program has been developed for three of Arlington's former residents. Finally, the Director of Community Services feels that the periodic review process has made staff more aware of the residents' developmental needs.

### 1.3.3 State Litigation Relating to Deinstitutionalization and Its Impacts

In both 1973 and 1974, the state was involved in litigation concerned with mentally retarded individuals. The 1973 suit was brought by a resident of Arlington and by friends of the resident, against the State Mental Health Commissioner and the Center. In fact, two separate issues were involved, one concerning peonage and one concerning right to treatment. The peonage suit has since been dropped, and the right to treatment suit is still pending.

In 1974, suit was brought by a former resident of Arlington and his attorney against the Superintendent of Arlington, the Center's Board of Trustees, and a judge who had recommitted the resident. The suit which is still pending, is concerned with illegal commitment and prevention of due process.

According to the Director of Community Services as Arlington, the suits have had relatively little impact on programs and activities at the institution. The 1973 suit against the Center did have a somewhat indirect impact on the quality of educational and pre-release programs at the institution, to the extent that the court indicated that every person has the right to treatment, and the legislature, in turn, appropriated more funds to the institution for the development of treatment programs.

## 2.0 CLIENT ASSESSMENT PROCEDURES

In 1972 and 1973, the assessment of clients while they were residents of the institution consisted primarily of an informal, subjective assessment by a multi-disciplinary team; that is to say, no specific testing instruments were used, and client assessment was based primarily of staff observations of the client's activities. In 1974, the assessment procedure became more structured, with more of an emphasis on interdisciplinary programming. According to staff, assessments in 1974 were primarily in the areas of psychological, educational and recreational activities; standardized instruments were used at this time.

Staff report that during the period under study, all residents had medical assessments twice a year. In 1972 and 1973, educational and vocational assessment occured once every two years, while in 1974, this was increased to once every year. Psychological assessments occurred either annually or bi-annually, depending on the resident, in 1972 and annually in 1973-74. Social assessments are considered to be an on-going process at Arlington. According to staff, the Center does not make a distinction in the frequency of assessments of its clients according to the anticipated release of each client; clients who are being considered for release in the near future are not assessed more often than those residents for whom there is no immediate expectation of release.

From 1972-1974, certain staff were consistently involved in client assessments; these included the unit director, physician, and various therapists. (The involvement of occupational, physical and speech therapists varies according to the individual client being assessed). In 1974, as Arlington moved toward an inter-disciplinary (as opposed to multi-disciplinary) approach to assessment and treatment, the vocational rehabilitation counselor, director, and direct care staff also became involved in client assessment. However, the vocational rehabilitation counselor is involved only if the client is being recommended for some type of vocational placement.

Clients released in 1972-1973 from the Arlington Developmental Center had no input into their assessments, and did not discuss their assessment results with staff. This situation changed somewhat in 1974, when approximately 10% of the released clients discussed their assessments with staff.

Involvement of outside person in client assessments for those clients released during the period under study was fairly minimal. In 1972 and 1973, families, guardians, and advocates were rarely invited to assessment sessions. No other persons or agency representatives from outside the institution were invited to participate in client assessments during this time. However, in 1974, families and guardians were invited to assessments and approximately 15% participated.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction

The Arlington Developmental Center operates three programs which are considered pre-release programs; it is important to note, however, that clients are not necessarily always chosen for participation in these programs with the implicit goal of eventual release. That is to say, clients are placed in the programs according to their ability and the available openings in the programs. Release from the Center is not specifically contingent upon the resident's participation or success in the programs. The three programs include:

- Shadowlawn, a special school operated by the county for children between the ages of 14-18;
- Progress House, a separate residential program with separate cottages for men and women aged 18 and over, located on the Arlington campus;
- Goodwill Industries and Sheltered Occupational Workshop, two sheltered workshops located in a large city some 20 miles from the Arlington campus.

### 3.2 Program Descriptions

#### 3.2.1 Shadowlawn

The Shadowlawn program is conducted by the county off the grounds of the institution. Clients in the program are between the ages of 14 and 18 years. Admission to the program depends upon an interdisciplinary staff recommendation, based on the functional abilities and readiness skills of the client. The primary goal of the program is to provide pre-vocational and additional academic training (i.e., in reading, writing, and math) to its students. The percent of released clients participating in the Shadowlawn program prior to release during 1972-1974 was fairly low, from 14% of the 106 released clients in 1972 to 8% of the 105 released clients in 1974.

Arlington clients who participate in the Shadowlawn program are awakened from 5:30-6:00 a.m. in their dormitories on the Arlington campus, bathe and dress themselves, and eat breakfast in the staff dining room. They then board buses which take them to the program located in the community. At around 2:30 p.m., they return to Arlington and then go back to their units to participate in structured leisure-time activities until dinner. After dinner, they return to their units for more structured leisure activities until retiring; bedtime is at around 9:00 p.m.

The types of training offered at Shadowlawn include: behavior management, academic skills, using community resources, simple money management, preparation for job applications and interviews, and to some extent, specific job skills. More basic skills such as self-help, personal hygiene, and pre-academics are not included in the Shadowlawn program since it is assumed that the client already possess these skills prior to entry into the program. Staff report that the types of training offered to clients enrolled in Shadowlawn did not change from 1972-1974.

Several types of training techniques are used in the program depending on the skill being taught. For behavior management skills, the main technique employed is behavior modification, with the prime reinforcer being suspension from the program if the trainee does not adopt the desired skilld. Role playing is used to teach both use of community resources and preparation for job applications/interviews. (Use of community resources is taught only in the classroom; no field trips are involved). Training in specific job skills includes refinement of gross and fine motor coordination, increase of attention span, and the use of such practical job-related skills as meal preparation and serving, cleaning, and small parts assembly. There is minimal Arlington staff involvement in the Shadowlawn program.

### 3.2.2 Progress House

The Progress House program is located on the grounds of the institution and is composed of two houses, one for women and one for men. Participants in the program are aged 18 and over and are admitted by an interdisciplinary staff recommendation, based on testing performed prior to the staff evaluation, and on individual staff member's personal knowledge of the client's case. The overall goals of the Progress House program are the refinement of daily living techniques and social skills that will enable clients' eventual return to the community. Approximately 18% of the 106 Arlington clients who were released in 1972 participated in the Progress

House program prior to release; this percentage dropped somewhat for clients released in 1973. However, in 1974, over 25% of the 105 released clients participated in this program. This increase was reportedly due to the fact that a men's Progress House cottage was opened whereas formerly the program had been only for women.

The morning and evening routines for Progress House clients is much the same as that for those attending Shadowlawn. However, most Progress House clients remain on campus throughout the day. Progress House clients are allowed to go to bed whenever they wish.

The types of training offered at the Progress House cottages to both men and women include the following: self-help skills, personal hygiene, sex education, and behavior management. In addition, some skills are taught only to men or only to women residents. For example, housekeeping skills are taught only to women, while use of community resources and money management are taught only to men.

Numerous training techniques are used in the Progress House cottages. For example, although training in self-help skills and personal hygiene during 1972 and 1973 was somewhat random, task analysis was introduced to teach these skills in 1974; this includes the assessment of each client's current skills in each area and the creation of programs to maintainthese skills. Housekeeping skills and some behavior management are taught on a one-to-one basis by the developmental technician, with the behavior management program having been set up by the unit psychologist. Behavior management skills in this case include respect for property, recognition of danger signals (e.g., stop lights), and appropriate social behavior (e.g., shaking hands rather than hugging and kissing). Sex education consists primarily of groupwork and "rap sessions" conducted by the unit social worker and behavior therapist. Use of community resources is taught during field trips, which are not necessarily limited to particpants in the Progress House program; recreastional field trips may include up to 25 people from the institution, while shopping trops are usually taken in groups of three. Most Progress House training has been coeducational since 1974, when the men's program was initiated.

Arlington staff involvement in the Progress House program, unlike the Shadowlawn program, has been fairly extensive. Participation by year remained fairly constant from 1972-1974, except for the cases of behavior therapists and vocational rehabilitation counselors, who began working with Progress House clients in 1973; naturally, the absolute number of various staff types working with clients also increased in 1974 when the men's program began. In all three years, the staff category which spent the most time with clients was direct care staff. In all three years, nurses spent the second largest amount of time with clients, psychologists the third, and social workers the fourth.

### 3.2.3 Goodwill Industries and Sheltered Occupational Workshop

Goodwill Industries and Sheltered Occupational Workshop offer contract work, which is used for evaluation and training of Arlington residents for job placement; there is also an extended employment component. Approximately one-third of the target clients released in 1972 had participated in one of these two sheltered workshops; this number doubled in 1974. Unit staff recommendations initiate possible placement in one of these two programs. Such a recommendation is then forwarded to the vocational rehabilitation counselor, who in turn makes a referral to the admissions committee of either Goodwill or Sheltered Occupational Workshop. Employees in Goodwill are considered to be more self-reliant then those in Sheltered Occupational Workshop.

The routines of Sheltered Workshop participants from Arlington are much the same as those in the Shadowlawn and Progress House programs. The primary difference in general routine is that Sheltered Workshop participants do not return to the Arlington campus until 4:00 each work day.

Training offered to Arlington clients in the two programs includes simple money management (making change), preparation for job applications and interviews, and specific job skills. In addition, clients at Sheltered Occupational Workshop receive what might be termed behavior management training, to the extent that they are taught to punch in and out of their jobs each day. Staff noted that the Goodwill program is currently in serious trouble, due to the fact that minimum wage laws have made it impossible for the program to continue paying its workers.

Clients entering Sheltered Occupational Workshop and Goodwill undergo a 20-day evaluation conducted by the vocational counselors at those programs. Evaluation instruments include McDonald, Wide Range Achievement, and Slawson's. Preparation for job applications and interviews and specific job skills are then taught by means of role playing, small group activities (with five clients or less), and individual task-oriented activities. These two program components are usually provided during a 40-day period following evaluation. Specific job skills are taught according to the individual's ability, and may include packaging, assembling, sorting or salvaging. There is no set course of instruction to teach money management; rather, this activity involves refinement of already existing skills through one-to-one interaction with workshop staff. Arlington staff have minimal involvement in the training of Sheltered Workshop participants, since this is an off-campus program. Between 1972 and 1974, the only staff particpants in the Sheltered Workshop programs were the vocational rehabilitation counselors, who spent about 60% of their time working with Sheltered Workshop participants.

## 3.3 Sequence of Pre-Release Programs

There is no prescribed sequence for clients moving from one prereleased program at Arlington to another. In fact, older students attending Shadowlawn may live at the men's or women's Progress House cottages, as may adults participating in one of the two Sheltered Workshop programs. Thus, if there is any sequence at all, it depends primarily on the client's age (i.e., children do not usually participate in the Sheltered Workshop program, and adults cannot participate in the Shadowlawn program). However, it does appear that most adults released into the community--and especially into group homes--have spent some time in one of the Progress House cottages. To some extent, therefore, the Progress House program could be considered an informal prerequisite to release into group home living situations. At the present time, there is an effort to have newly-created group homes include one "respite bed." Clients who are soon to be released form Arlington would spend a short time--perhaps one week--living in the group home, then return to Arlington until their official release. This program, it is hoped, would ease the client's transition into the community.

## 3.4 Overall Characteristics of Pre-Release Programs

According to staff, the major strength of the pre-release programs at Arlington at the present time lies in the emphasis on individualized programming and in the staff's efforts to adapt programs for each client according to her/his individual functioning ability and needs. The second greatest strength is seen to be in the institution's gradual movement toward interdisciplinary as opposed to multi-disciplinary activities. Multi-disciplinary is defined here as a case in which each staff member works with the client according to his/her specific discipline (e.g., educator, psychologist, social worker), with very little exchange or interaction among staff. Interdisciplinary activity, by contrast, involves all staff members working together, regardless of discipline on the needs of the client. Interdisciplinary operations are seen by staff to be more constructive and less rigid than multi-disciplinary. All staff working with a client are thus involved in the decision-making process for that clinet.

A major weakness in the pre-release programs at Arlington is seen by staff to be the lack of systematic task analysis or evaluation procedures for these programs. Although task analysis is used in some specific areas, staff feel that this technique should be employed more heavily in developing and implementing programs and that more systematic evaluation procedures are needed to determine the programs' effectiveness. A second major weakness of the Arlington programs as perceived by staff, relates to the institution's geographic inaccessibility to the community. Staff feel that is is a tremendous hindrance to be located some 20 miles from any major concentration of population, where a variety of experiences would be available to clients. Because of this distance, any field trip to the city must almost always involve from 20-30 clients, in order to be economically feasible. However, when this large a group is involved, its members are almost often seen as "those people from the institution" which would not necessarily be the case for smaller groups of three or four.

The main efforts to overcome what staff perceive as wekanesses in the institution's pre-release programs have consisted of a continual push toward the interdisciplinary approach and individual programming. Although it is obvious that Arlington cannot resolve the grographic inaccessibility problem, staff have become more aggressive in attempting to educate or condition the community about Arlington residents, and to promote acceptance of its residents prior to and during their re-entry into the community.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

Release procedures at the Arlington Developmental Center have essentially been the same since 1972. Procedures differ somewhat, however, for releases to group homes and releases to natural families.

In the case of group homes, release depends primarily on an opening in one of these homes. (The plan is to have 50% of the residents in a group home from the institution, and 50% directly from the community; at the present time, group homes have approximately 70% of their placements from the institution,and 30% from the community). When a place is about to become available in a particular group home, the Director of Community Services at Arlington is notified of the expected vacancy. He in turn notifies the various unit teams of the type and the location of the home. The unit teams then meet and decide on any recommendations which they might have for group home placement within their units. These recommendations are then forwarded to the Director of Community Services. He looks at these recommendations in terms of the functional levels of the clients recommended, their behavior characteristics, the availability of daytime programs for them, and the overall appropriateness of the group home setting for the client. If he concurs with the recommendations, the social worker who is assigned to the county where the residence is located is contacted. The social worker then notifies the admissions committee of the group home who then make the final selection. This process, which is considered by staff, to be somewhat inefficient, will be changed by the creation of a placement committee, consisting of a regional office representative, a social worker, the Supervisor of Special Education at Arlington, the Chief Psychologist, and the Director of Community Services. Unit team recommendations will go directly to the placement committee, which will make the decision as to the most appropriate individual to be placed in the group home.

When a client is to be released to his/her natural family rather than to a grouphome, the only people involved in the release process are the unit team, the social worker assigned to the county in which the family lives, and the family itself.

The three most important cirteria used to determine whether a client is ready to be placed in the community , in order of priority, are as follows:

1) Functional level of the client
2) Availability of day program alternatives in the community; and
3) Availability of residential placement opportunity in the community

### 4.2 Factors Affecting Release

Staff at Arlington feel that the main characteristics of a client who is easy to place is a low incidence of behavioral problems (e.g., no severe acting out, no severe temper outbursts). Degree of retardation is not considered to be a limiting factor in community placement. For example, one of the institution's most successful group home placements is a 27-year old man who tested at an IQ of approximately 12, but who also has extremely well developed social skills. He had been institutionalized since the age of 10, and is now doing very well in one of the group homes used as a placement resource by Arlington.

Conversely, clients with behavior problems are considered by the Arlington staff to be among the most difficult to place. The main problem, according to staff, is that the general community will not accept retarded persons who are predisposed to behavioral or emotional outbursts. Similarly, people in the community are reluctant to deal with retarded individuals whose looks are "different" because of their disability. The staff at the institution feel that these difficulties can be partially resolved by a program of community education, which will help individuals to accept semi-ambulatory and cerebral palsied retarded persons. Although Arlington Developmental Center has no formal community education program, there is a speaker's bureau whose members are available to speak to various community groups, and who periodically make appearances on radio and television shows. In addition, they publish the "Arlington Tribune" on a quarterly basis, which gives information about activities and operations at the Center to all client families and other interested persons.

Arlington has no policy regarding the matching of specific types of clients with various placement settings. The first priority is to place the client with his/her natural family. If this is not possible, clients are placed as close (geographically) to their families as feasible, in order to facilitate family visits. If this is not possible, the institution places clients in settings that seem "most appropriate." In all cases, the client him/herself is consulted in regard to placementm and can refuse a particular type of placement if s/he wishes.

### 4.3 Client Status Upon Release

In 1972 and 1973, the majority of releases of clients into the community were family-initiated. This changed in 1974, when slightly over half of the releases were institution-initiated. This change is due to the fact that more group home placements were available in 1974 and placements into group homes are initiated by the institution.

The Arlington Developmental Center employs three release categories (1) "Trial visit," in which the client is initially released for a 30-day period, which may then be extended by a group residence board if they so desire. This category would be comparable to the study definition of extended visit. (2) "Conditional discharge," in which the client is discharged (i.e., no longer on the official roles of the institution), but may return to the institution and be readmitted within one year of discharge; conditional discharge status may also be extended beyond the year. If it is not extended, the client must go through the entire admission process in order to be readmitted. Clients on conditional discharge usually receive some services from the institution. (3) "Absolute discharge," in which the client's name is completely removed from the rolls of the institution (e.g., after the year of conditional discharge). Very few clients receive absolute discharge when first released from the institution. Of the group released from Arlington in 1972-1974, all were on "trial visit" status at the time of their discharge. In 1972, clients released on trial visit could retain this status indefinitely. In 1973-1974, released clients could retain trial visit status for one year.

The original commitment status of the client has no effects on her/his legal powers except in one area: if the client has been committed to the institution by a court, s/he cannot be released from the facility without court permission. The Superintendent must notify the court in the case of placement in the community. However, in recent years, most admissions have been voluntary and thus, court approval is increasingly less needed. In addition, if a client is under 18 years of age, s/he cannot be discharged without the family's approval. If a person voluntarily entered the institution and is over 18 years of age, s/he may leave the facility at his/her request.

Once the client has been placed in the community, there are no limitations on her/his legal powers. However, although the client can legally refuse medical or other services offered by the facility, in actual practice staff report that this is fairly difficult.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

Follow-Up procedures differ for clients released to group homes and those released to their natural families. If the client is released to her/his natural family, the institution does not initiate any follow-up; follow-up only occurs in those cases where the client's family or the client request some sort of follow-up support services. According to staff, this happens relatively infrequently, perhaps once a year for most clients.

According to staff, two types of follow-up activities take place in the case of clients released to group homes: (1) Follow-up statistics are kept by the institution, as group homes are required to report to the institution on released clients on a quarterly basis. At present, this report consists only of confirmation of occupancy in the group home (i.e., "Client X is still here."). In the future, staff report, this reporting system will become more formal so that the group home will also notify the institution of any change in the client's status, such as a change from day activity center to workshop placement. (2) Follow-up support services consist of on-going visits from the institution's social worker to the persons in the group home.

In 1972, 1973 and 1974, many types of follow-up procedures were used depending on the nature of the follow-up activity. These procedures include letters, telephone calls, and regular visits to the client's group home setting. Follow-up is also performed by agencies other than the institution. In most cases, this agency is the Department of Public Welfare, especially where the client is under Department guardianship, or is receiving welfare payments. Staff noted that follow-up by the Department of Public Welfare is usually somewhat more extensive than that performed by the institution. However, institution social workers maintain regular formal communication with Department of Public Welfare personnel concerning released clients.

Staff report that clients in group homes are followed up at least once a month, while clients who have returned to their natural families are usually followed-up at least twice a year. For 1972-1974, approximately 98% of those clients placed in group homes were followed-up by the institution. The number of clients released to their natural families who have been followed up is difficult to estimate since, as has been noted above, follow-up for these clients is contingent on family initiation.

## 5.2 Support Services

### 5.2.1 Agencies with Continuing Responsibility for Client's Welfare

Once a client is released on extended visit status, primary continuing responsibility for ensuring the individual's well-being is shared by the institution and a designated private agency specializing in mental retardation services, which in most cases, is the group home to which the client has been released. Once the client has been discharged, this responsibility is held primarily by the group home. In the case of clients released to their families, the responsibility for their well-being rests with the family.

When a client is released into the community on either trial visit or conditional discharge status, s/he has the right to return voluntarily to the institution within one year without regard to waiting lists or waiting periods. Although there is apparently no formal regulation at Arlington concerning such a situation, the institution feels that it has a moral obligation to re-accept the client. Clients cannot be returned to the institution involuntarily.

### 5.2.2 Types of Support Services Provided to Clients

According to staff, in 1972, 1973, and 1974, social services were provided to 45% of released clients; this figure represents a combination of those clients released to group homes, approximately 100% of whom received follow-up social services, and those released to their families, only limited numbers of whom received social services. The percent of clients receiving medical services (primarily medication regulation such as anti-convulsants) rose slightly over the three-year period, from 10% to 23%, because more people were released from the institution toward the end of that period. Psychological services, primarily re-assessments, were provided to approximately 40% of the population during the three-year period. Those released clients not receiving psychological services from Arlington received them from community mental health centers, of which there are 10 in the western third of the state (five in the county in which Arlington is located).

From 1972-1974, an increasingly large number of released clients were receiving support services both in their natural homes and in group homes. The percentage of clients placed in their natural homes who received support services rose from 10% to 60% over the three-year period, while the percent of clients in group homes who received support services rose from 70% to 98%. As for the differentiation of service provision according to release status, services were provided to a much greater percentage of clients on extended visit than to those on discharge status. In the three-year period, virtually none of those clients who had discharge status received follow-up support services from the institution. During this period, the number of clients on extended visit status who received services rose from 30% to 40%.

During the period 1972-1974, staff involvement in provision of support services did not vary. The types of staff who provided support services, ranked by the amount of time spent providing such services, included: social workers, psychologists, vocational rehabilitation counselors, physcians, speech therapists, physical therapists, educators, and regional' office staff.

Staff consider the social work and psychological support services provided to released clients during the years 1972-1974 to have been adequate. Medical services were considered to be adequate during this period.

### 5.3 Support Services Provided to Those Responsible for Released Clients

In 1972, no support services were provided to the families of released clients. These provision services began in 1973. During this year, a few natural families did receive support services in the form of individual behavior programs or physical recreation programs. These usually consisted of instructions to the parents by the behavioral or physical therapist provided at the time of discharge (e.g., on how to use special devices needed by physically handicapped children).

Support services to the "families" serving as staff for group homes consisted of in-service training and follow-up training. Although group homes are usually run by private organizations, Arlington works with their private contractors in the selection and training of group home parents. Those selected are usually people in their mid-40s who have already had children of their own, and who seem to be highly motivated, honest, and even-tempered. When the staff of a new group home has been selected, the In-Service Training Department at Arlington provides them with individualized training, which can last anywhere from two days to a week. Training is primarily carried out through lecture and audio-visual techniques, although there is some one-on-one training and some preliminary client contact. Areas of training include understanding mental retardation, basic management techniques, administration of medication, dietary principles, working with the families of clients, etc. Follow-up training for group home parents is provided by the institution and by a group from another state, as well as by two nearby universities. Follow-up training usually consists of workshops to improve specific skills.

Arlington also provides training to the staffs of other community programs dealing with mentally retarded clients, including adult activity centers, day training centers, and infant stimulation programs. Such training includes lectures, workshops, and individual consultation. One statewide workshop is provided annually, and the institution tried to provide one regional workshop annually as well, in additionto periodic workshops provided throughout the year for specific groups.

In 1972-1974, no direct training was provided by the institution to the teachers and employers of released clients. However, in 1973 the institution began serving as a field placement for nursing, psychology and social work students from local colleges and universities. Students do their practica at the institution in either classrooms or cottages and dormitories.

### 5.4 Institution's Assessment of Released Clients' Adjustment to Community Living

The Arlington Developmental Center conducts no formalized assessments of clients' adjustment to community living at this time.

## 6.0 RELEASED CLIENT PROFILE

As stated in section 1.0, released clients during the 1972-1974 period were grouped into two categories: "target and "non-target" clients.* Information will first be presented on the entire deinstitutionalized population of 1972-1974 and secondly, on the target and non-target populations. As the focus of this study is on the released target population, more data was obtained for this set of people than for the non-target clients.

Overall release rates varied slightly during the three years under study. In 1972, 106 clients were deinstitutionalized representing 19% of the total institutional population. In 1973, 99 clients were released, or 17% of the population enrolled at the Center for that year. Finally, in 1974, another 105 mentally retarded persons were released, constituting 19% of Arlington's overall population for that year. Thus, between 1972 and 1974, a total of 310 mentally retarded people were placed in community settings or other facilities.

Over half of the released persons during this period were either severely or profoundly retarded. Twenty-three percent of the total group were severely retarded, and 43% were profoundly retarded; mildly retarded persons constituted 15% of the group, while moderately retarded persons accounted for 19% of the released population from 1972 to 1974.

The majority of those released were aged 18 and under (56%), while 44% or 136 residents were adults. During the three years of study, more males were released than females.

The most frequent residential placement for the released population was to natural/adoptive homes, where 68% of the released clients were placed. The next most common placement was to group homes where 13% were placed. 10% went to independently living situations, 9% to other institutional facilities and less than 1% to foster homes and/or nursing homes.

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* See Glossary for definitions of target and non-target clients.

The most common handicapping conditions in addition to mental retardation of the released population were mobility problems, epilepsy, and psychiatric problems.

## 6.1 Demographic Characteristics of Target and Non-Target Clients

Of the deinstitutionalized clients, the released target population for 1972 was 22 people, or 21% of the 106 who were released during the entire 3 year period. The target group comprised 31% of the released population in 1973, while in 1974, 35% or 37 of the 106 released clients were target clients for this study. A further breakdown indicates that the target group represents 4% of the total institutional population in 1972, 5% in 1973, and 7% in 1974.

Non-target clients were more numerous than the target clients. In 1972, 84 non-target clients were released representing 79% of the deinstitutionalized population for that year and 15% of the entire institutional population. Sixty-eight non-target clients were released in both 1973 and 1974, or 12% of the institution population for each year.

The majority of the clients were adults during the 1972-1974 period (79%) while of the non-target group, 70% were children or youth (ages 6-18 years). The sex of the target clients varied slightly during the 3 year period under study. In 1972 and 1974, the majority of those released were males while in 1973, 53% of the released target group were female. The non-target clients were approximately 43% female during all three years.

The level of retardation among the target group was fairly evenly distributed across all four level categories. Twenty-six percent of the target clients were mildly retarded, 32% moderately retarded, 27% severely retarded, and 16% profoundly retarded. Among the non-target group, profoundly retarded adults constituted over half the entire group (55%). Severely retarded clients were the next most frequently released (22%), while 13% were moderately retarded, and 11% were mildly retarded.

The primary additional handicap of the target clients released from Arlington Development Center was mobility limitations (including spasticity, confinement to wheelchair, etc.), approximately one-third of the target clients in all three years had this additional handicap. The second most common handicap was deafness, occurring in about 10% of the target clients. According to the Director of Community Services, many of the target clients released during the 1972-1974 period had mild behavioral problems as well (e.g., occasional temper tantrums or outbursts) but none of these were serious enough to be classified as major psychiatric problems.

Non-target clients had the same types of additional handicaps as the target population but in a greater frequency. Nearly three-quarters of the non-target group had mobility problems, over half were epileptic, and more than a third had psychiatric problems.

### 6.2 Skills of Target and Non-Target Clients Upon Release

According to staff, almost all of the clients released from Arlington Development Center between 1972 and 1974 possessed skills in the areas of self-help, personal hygiene, and behavior management, as well as having some pre-academic skills. Less than half of the clients released in the three years had skills in the areas of housekeeping and money management, or in reading, writing, and math. Staff report that all of the released clients had pre-vocational skills, but only one-fifth had specific job skills. Virtually none of the clients released during the three years possessed knowledge of birth control techniques or skills in preparation for job applications and in using public transportation. In only one area--using community resources--did client skills decrease from 1972 (40%) to 1973-1974 (25%). This was related to the fact that in 1972 and early 1972, the only available community (non-family) placement for Arlington clients was a halfway house which received clients on contract from Arlington. Clients released to this halfway house needed more extensive community skills than clients released in later years to other, more structured (usually rural) placements which became available as of 1973. These other placements are mostly group homes which serve from four to eight persons, many of whom are severely retarded. The clients in these placements are expected to be long-term residents; due to these clients' lower potential for upward movement, the Arlington staff felt that they did not require extensive knowledge of community resources in order to make a successful adjustment.

In fact, the Arlington staff expect that released clients in the future will exhibit fewer cognitive skills and a lower ability to use community resources, since all of those clients with high functioning levels have been or are being released to the local halfway house or other similar community settings. Little by little, as group home placements become available, Arlington is releasing its clients who could not make successful adjustments to independent or semi-independent situations, but who are nonetheless fully able to function in a structured group home setting.

## 6.3 Residential and Day Placements of Target and Non-Target Clients

Arlington Development Center does not consider itself a long-term residence, though staff admit that some of the most severely or profoundly retarded may spend their lifetimes there. A variety of community placements are utilized for those clients who can successfully function in such environment after having learned the necessary skills for community living. The most frequent type of setting to which both target and non-target clients were released was to natural/adoptive homes. Sixty-six percent of the target population and 72% of the non-target population were so placed. Group homes received 34% of the target population and 4% of the non-target group.

Given the definition of non-target clients, it was not unexpected that non-target clients would show a high percentage of nursing home or other similar-type facility placements. One non-target client during this period was placed in a nursing home while 13% were placed in other facilities or institutions. According to the Director of Community Services, Arlington is beginning to explore nursing homes as a resource for placing non-ambulatory clients. The Director notes that such clients "will be discharged from the institution to a nursing home with a specific program which we will require the nrusing home to carry out."

Since 1972, the number of clients who visited their residential setting prior to moving steadily increased. By 1974, all the clients placed into the community had visited their setting to which they moved before being released from Arlington Development Center.

During the 1972-1974 period, the day placements of many of the released clients who were placed in their natural/adoptive homes is not known by the Arlington staff. These placements were arranged by athe client's family and were not reported to the institution. Among those placements known to Arlington staff, the most popular type was workshop placement; almost half of the known day placements of target clients were to workshops. The second most frequent day placement was to day activity centers, accounting for about one-third of the known target client placements in 1973 and

1974. Public school programs were also utilized for released clients. Information on the range and frequency of day placements for the non-target population was not obtained.

## 6.4 Readmissions

The number of target clients released from Arlington in 1972, 1973 and 1974 and subsequently readmitted to the institution has remained relatively low, ranging from 14% to 7% per year. However, it must be remembered that Arlington is a fairly new institution, which only began releasing a large number of clients in 1973, and thus, staff feel that these favorably low percentages may increase over time. Virtually all readmitted clients were adults (100% in 1973 and 1974), and in most cases, they were males.

All clients released to the community and subsequently returned to the institution were placed in one of two settings upon their original release: natural home or group homes. The percent of clients released to group homes and later readmitted to Arlington from this setting has been steadily increasing. Over one-third of the clients readmitted in 1972 were from group homes, while this number rose to three-fourths in 1974. It is important to note, however, that this increase might in fact be related to the proportional increase in releases to group homes (as opposed to other settings) over the recent past.

All of the clients released in 1972, 1973, and 1974 subsequently readmitted to the institution returned within six months after initial release.

Arlington keeps no case-by-case records of the reasons for readmission for clients. However, staff stated that there are, in almost all cases, two possible reasons for readmission: (1) behavior problems which make the client unmanageable in his/her natural home or group home; and (2) breakdown in the family unit of clients released to their natural home.

## 7.0 PROFILE OF RELEASED STUDY GROUP

Of the 90 target clients released from Arlington Developmental Center during 1972 through 1974, 24 or 27% were interviewed during July and August of 1975 and are referred to as the study group (see Glossary). In addition, one member of the study group had returned to Arlington by the time of the interviews and was interviewed there. In this section information gathered from institutional staff, records, the study group member, his/her family, housemanager, social worker, or other contact person in the community who was interviewed about the study group member will be presented. The information is not intended to serve as a validation of the information gathered from the institution about training, services, or follow-up provided to released clients, nor is it intended to be a "follow-up" of the released clients. Rather, it provides another view of the deinstitutionalization process. The descriptive information will be presented on the types of clients interviewed from Arlington Developmental Center as well as the study groups' perceptions of their problems since release. In addition, information will be presented from the families of the released clients on the institutional follow-up, the types of services received, and the types of problems encountered since release.

### 7.1 Study Group Characteristics

The ages of study group members ranged from 12 to 48 years, with an average age of 26 years. Virtually all of the study group was white. Close to half (44%) of the study group clients were mildly retarded, over a third (35%) were moderately retarded and over a sixth (17%) were severely retarded. About 5% of the study group clients had no recorded level of retardation. The most common additional handicaps other than retardation were speech impediments (30%) and psychological problems (13%).

### 7.2 Residential and Day Placements

#### 7.2.1 Residential Placements

While nearly half (48%) of Arlington's released study group were initially placed in group homes upon release, about a third (35%) were living in such settings when interviewed. Approximately the same proportion were initially released to natural/adoptive homes (22%) as were in these settings when interviewed (26%). Although 17% of the study group clients were initially released to independent settings, at the time of the interviews nearly a third (31%) of the clients were in independent settings. About 9% of the study group was initially placed in semi-independent settings, and 4% were in such settings at the time of the interviews. Foster homes were the initial and current placement for 4% of the study group.

### 7.2.2 Day Placements

According to the family respondents of the study group, over half (52%) of the clients were initially placed in either competitive employment situations or sheltered workshops. Over a third (35%) were initially placed in a day activity program, and over a quarter (26%) of the study group clients at Arlington were initially placed in a school program. Two clients initially were not placed in any day program (9%).*

At the time of the interview, nearly a quarter (22%) of the group study clients had changed day placements at least once. Over a third (39%) of the clients were at the time of the interview, in competitive employment or sheltered workshop situations. Also, over a third (35%) of the clients were placed in day activity programs, and nearly a quarter (22%) were in school programs.

Almost a tenth (9%) of the study group reported that they were not involved in any day program, with the most common reasons for not participating being either that there were no appropriate programs or jobs available in the community and that everyone in the community was having a problem finding employment.

## 7.3 Institutional Follow-up and Study Group Clients

Families of the study group clients were asked if anyone from the institution had follow-up contact with the client after release. Almost all of the respondents (92%) reported that there was some follow-up from an institutional staff member. The most frequently stated method of contact was by visitation to the client's residence. Other common types of follow up were by phone conversations and by contact through the client's community social worker or someone responsible for the client.

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*Because of the possibility of multiple day placements, percentages exceed 100%.

The amount and frequency of follow-up contact tended to decrease over time. While nearly three-quarters of those followed-up during the first six months after release reported monthly follow-up contacts during the six months prior to the interview, monthly follow-up contact was received by less than half the group. During this latter period, 9% reported yearly contact while another 9% reported no follow-up contact.

The family respondents were asked how satisfied they were with the follow-up provided by Arlington. The majority of the respondents (70%) were satisfied with the follow-up received, while 17% were dissatisfied, and 4% said they were neither satisfied nor dissatisfied with the follow-up provided.

## 7.4 Case Managers and Study Group Clients

Nearly all (96%) the study group members reportedly had a case manager, or someone who was responsible for the client's well being and for assuring on-going support services for the clients. For the majority of the study group clients (67%) the person cited as casemanager was the parent or houseparent. Thus, not surprisingly, the frequency of contact was most often cited as daily.

## 7.5 Services and Training

### 7.5.1 Services and Training Needs

Family respondents were asked about the support services and training used by the released study group.* The services cited most often as needed but not received by the study group were speech therapy (noted by almost one-quarter of the respondents), social and/or psychological counseling, and recreation programs. The types of training cited most often as needed but not received were language skills, vocational training and dealing with emergencies.

The support services most frequently mentioned by the family respondents which they felt they needed but did not receive were support and/or training prior to the client's coming to the residence and on-going family counseling.

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*See Glossary for the list of support services and training on which information was collected.

### 7.5.2 Services and Training Use

Family respondents were asked about the clients' use of various support services and about the clients' training in various skill areas since release from the institution. The study group reportedly used an average of four support services since their release, while they reportedly received training in an average of ten skill areas.

Family respondents were also asked about the providers of services and training received by Arlington's released study group. Of the services used by the clients, respondents reported that over half (51%) were received from a community agency, while a quarter (25%) were received from the clients' day programs. The community residences where the clients were placed reportedly provided 17% of the services, while Arlington Developmental Center provided 3% of the services. Other community sources provided 5% of the used services.

Of the training received by Arlington's released study group, almost all of the training was provided by either the clients' day programs (44%) or by the community residences (42%). Community agencies reportedly provided 14% of the training, while no training was provided by either Arlington or other community sources.

## 7.6 Problems

The family respondents of the clients were asked a series of questions about the types of problems and the degree of severity of those problems that the study group encountered since release. The most common problems cited by the families were socially unacceptable behavior, family relationships, loneliness, grooming, and keeping a job.

Study group members were asked which problems they considered to be the most difficult since leaving the institution. The largest number of people cited medical problems. Other difficulties mentioned included family relationships, loneliness, psychological problems, and budgeting money!

## 7.7 Interviewers' Perceptions of Study Group Adjustment

Following each interview, interviewers recorded their perceptions about the study group member's adjustment to the community along three dimensions: degree of social isolation, client satisfaction/happiness with his/her life in the community, and the overall adjustment of the client to the community.

Over half (56%) of the study group clients were perceived as having some social relationships with others, while only 17% were perceived as having many social relationships. Over a tenth (13%) of the clients appeared to be somewhat isolated from the community, while the interviewers were unable to judge the social isolation of the remaining clients (13%).

Nearly three quarters (70%) of the study group clients were perceived as being either somewhat or very satisfied with their current lives, while only 9% seemed unhappy, and 13% seemed somewhat unhappy. The interviewers were unable to assess the happiness of the remaining 9% of the study group members.

Finally, the study group's overall adjustment to the community was judged by the interviewer. Almost half (48%) of the clients were perceived as being well adjusted to living in the community, while 13% were seen as being poorly adjusted. Nearly a quarter (22%) of the clients were perceived as being somewhat adjusted to the community, and the interviewers were unable to judge the adjustment of the remaining 17% of the study group clients.

# CHAPTER 4.0: BELCHERTOWN STATE SCHOOL

## 1.0 INTRODUCTION

### 1.1 Overview

The Belchertown State School, a public residential facility for mentally retarded individuals located in a rural area of western Massachusetts, is an institution in great transition. There have been several national, statewide and local events related to communitization* which have had an impact on Belchertown's own communitization policies and procedures. However, the staff at the School feel that the institution has not only been a reactor to outside events and pressures. They believe that they have actively pursued policies to develop better programs both at the institution and in the community to facilitate the movement of its residents from institutional to community life.

Belchertown's orientation to communitization reflects a two-fold approach: (1) preparation of individual clients for eventual placement in the community; and (2) preparation of the community for the client's entry. The staff at Belchertown feel that traditional "deinstitutionalization" models place too little emphasis on the second factor, community preparation. It is the feeling of staff that a community's ability to accept and provide support to clients released from institutions plays a major role in the client's adjustment to that community. In short, they believe that the social and environmental factors related to community adjustment must be stressed.

The clients who were released from Belchertown State School in recent years (including our "target" population -- see Glossary) differ significantly from the kinds of clients who are currently residents at the institution. According to staff, the majority of clients who were released from Belchertown in past years were admitted to the institution primarily for reasons other than mental retardation. Basically, these clients had originally been placed in the institution because they were socially disenfranchised and because no appropriate services existed in the community for them at the time of their admission. These persons included wards of the state, victims of child abuse, illegitimate children and impoverished persons. As the movement to place institution residents in community-based settings evolved, these were the first persons to be released from Belchertown State School. They were, in a sense, the easiest persons to place since they were very minimally retarded and they had few or no medical problems or other handicaps. This group of persons is in great contrast to the present population at the institution, who are more severely mentally retarded and tend to have medical and other handicaps as well. According to staff, the current population will be more difficult to prepare and place into community settings. Moreover, new support systems will have to be developed to meet the more extensive needs of these clients when they are released.

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*Belchertown State School uses the word "communitization" as opposed to "deinstitutionalization" because the staff at the institution believe "communitization" stresses the potential of citizens who were disenfranchised in the institution to be reabsorbed into the framework of the community. Because the staff at the school feel strongly that this term should be used instead of "deinstitutionalization", we have used "communitization" in this case study instead of "deinstitutionalization".

Belchertown's overall population has decreased steadily since 1972. During the 1972 to 1974 period under study, there was a 15% decrease from approximately 1,021 residents to 863 residents in 1974. Current (1975) population figures show another 9% reduction to 788 residents. While the proportion of males to females remained stable during this period and currently (consistently around 47% female) and while the age level of the residents has not varied (27% aged 18 and under) the distribution of residents according to levels of retardation has shown one of the effects of the communitization of higher functioning residents. For example, in 1972, nearly a quarter of Belchertown's residents were either mildly or moderately retarded while currently, only about 15% are mildly or moderately retarded. Less than half the 1972 residential population was profoundly retarded (45%) whereas in 1975, 54% were profoundly retarded. Thus, while the total population of the school has decreased, the proportion of lower functioning residents has increased.

In addition, the incidence of handicapping conditions other than mental retardation has shown a slight increase during this period and currently. Staff note, however, that improved diagnostic procedures have been instituted at Belchertown, possibly accounting for the identification of more residents with particular medical problems. The most common additional handicap of Belchertown's residents has been mobility limitations, affecting about 18% in 1972 and over a quarter of the residents in 1975. Epilepsy and blindness are the second and third most common additional handicaps, both of which have increased in number of clients affected since 1972.

The process whereby residents are admitted to Belchertown has undergone change in recent years. Court commitment formally was required for any resident older than 12 years of age. Currently, however, all residents are considered "voluntary admissions" except for minors whose parents or guardians authorize their enrollment.

Belchertown's overall budget has shown increases since 1972. There was a 24% increase in overall expenditures between 1972 and 1974 (from a little under $7 million to over $8 million in 1974) and there was another 9% increase between 1974 and 1975. In addition, the staff employed at Belchertown State School increased by 10% between 1972 and 1974 (from 802 staff in 1972 to 886 staff in 1974). The staff categories which show the greatest increases were the attendant positions (from 35% of the total staff to 42%), therapists (from 2% to 4% of the total staff), and administrators (from 4% to 7% of the total staff). Decreases were noted in the support staff category (from 42% of the total staff in 1972 to 31% in 1974). The number of certified and non-certified teachers dropped from 14 in 1972 and 1973 to none in 1974.*

## 1.2 State Context

### 1.2.1 State's and Institution's Communitization Policies

The state's communitization policies and philosophy have evolved over the past decade, partly in response to federal legislation such as the 1966 Community Mental Health and Mental Retardation Act, and partly in response to communitization trends within the state. Some of the underpinnings of the state's communitization policy include the development of a ten-year state Mental Retardation Plan in the mid-1960s to improve services to mentally retarded citizens, the appointment of a statewide legislative commission to examine the deficiencies of state institutions for the retarded and the initiation of federal court action in a "right to treatment" suit.

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*Staff increased between 1974 and 1975 as well (from 886 staff to 917, a 3% increase). Attendants and support staff showed the major increases.

While staff feel that the philosophical basis of the state's policies is well-established, the major effort lies in operationalizing established goals. According to the Superintendent at the School, it is no longer necessary to document the deficiencies of the present institution, or to document that it is in need of drastic change. Rather, the tasks lie in implementing the necessary changes, in developing new programs and services, in training new staff, and in helping society to accept communitized clients. In 1974, the Belchertown State School developed a Regional Residency Plan which attempts to implement some of the state's communitization goals. It calls for a service delivery system comprised of a region-wide continuum of community alternatives in "normal life settings." Belchertown has established a mechanism for the systematic review of available resources both within and outside the institution. As a result of the combined efforts of staff members at the School and in the Region, and with the support of the residents' families, a team process has been established that is geared to the delivery of viable human services to the clients.

## 1.3 State Legislation Relating to Communitization

### 1.3.1 The Right to Education Law and Its Impacts

Under state law, as enacted in 1972, local school districts are responsible for the education of all children with special needs, from age 3 to age 22. Special needs are defined as the "inabilities of a child to progress effectively in regular classes," because of adjustment difficulties arising from intellectual, sensory, emotional and/or physical factors, or specific learning disabilities. In effect, all handicapping conditions and all levels of handicaps are covered by this legislation.

According to the Superintendent of Belchertown, this law represents a major philosophical breakthrough, but for all practical purposes it has not yet been implemented. Staff report that between 1972 and 1973, this law was not implemented but that in 1974 it was in a stage of initial implementation, i.e., less than 10% of all school-age clients were provided an education according to this law. Funds for the staff positions necessary to implement this type of sweeping legislation have not been made available by the state. Belchertown staff have made continuing efforts to work with public school systems in meeting their responsibilities, and were repeatedly doing so even before this legislation was passed. The School has attempted to share some of its staff with local school systems, but it is felt that new staff and funds must be made available in order to implement the law adequately. In fact, the institution recently brought the State Department of Education to court to provide the necessary resources for implementation of this legislation. Thus far, the only response has been the provision of one Department of Education staff position to Belchertown; this is an Assistant Superintendent of Children's Services, who is responsible for working with local school districts in providing educational services to Belchertown residents.

The other impact of this law to date has been an increase in the number of clients released into the community from the institution: eight clients were released from Belchertown into group homes because educational programs were made available to them by their local school districts.

### 1.3.2 The Periodic Review Law and Its Impacts

According to state law, all clients in institutions must be reviewed by an interdisciplinary team on a periodic basis to determine the appropriateness of continued institutionalization, and to document changes in each resident's condition. The law mandates that each client be reviewed upon admission, during the first three months of residence, and during the second three months, and annually thereafter. The law, which was enacted in September of 1970, was partially implemented at Belchertown in 1972, and fully implemented by 1973 and 1974, with, staff report, between 85% and 100% of institution clients reviewed through this process.

According to Belchertown staff, this law has had the following impacts at the School:

- Increase in the number of clients served by educational and pre-release programs at the institution;
- Increase in the number of clients followed up by the institution on a regular basis;
- Small increases in the number of clients participating in educational programs in the community;
- Small increase in the number of clients receiving other services and participating in other programs in the community;

- Very significant increase in the number of clients released from the institution into community settings;
- Decrease in the number of clients returning from the community to the institution;
- Small increase in the number of severely handicapped clients placed in the community;
- Increase in the age of clients placed in the community;
- Decrease in the number of clients placed in foster homes (decrease due to the finding that many foster homes were inadequate);
- Increase in the number of clients placed in nursing homes and other institutional settings; and
- Small increase in the number of clients placed in group homes and semi-independent living situations.

### 1.3.3 State Litigation Relating to Communitization and Its Impact

One of the major impacts on Belchertown's communitization policies has been effected by a class action suit brought against the Department of Mental Health by friends and family members of 26 residents at the School. The plaintiffs charged that cruel, inhumane treatment existed at Belchertown, resulting from inadequate staffing, programs, and environment, and that residents were being denied their constitutional rights under the first, fifth, eighth, and fourteenth amendments. This suit was settled in late 1973 by consent decree. The initial settlement called for $2.6 million for renovation of the physical living environment, and for new staff positions at the institution. The physical renovations, which are currently underway, include redesign of existing buildings to approximate a more homelike environment. Many living units are being renovated as apartments and cottages, including individual bedrooms and kitchens for residents' use. A total of 116 new staff positions were also allocated under this court settlement, including 80 domestic aides (who will relieve current attendants of their domestic tasks so that they can instead work more directly with clients) and 36 new professional staff (to develop more comprehensive programs for residents). In addition to this initial settlement, the decree calls for additional planning programs in the following areas: admissions policy, personal hygiene, clothing, recreation, safety, seclusion and restraint, individual rehabilitation plans, records, medical care, resident progress reports, community placement policies, civil rights and privileges, repairs, education, food services, dental care, and resident labor. Beyond the capital renovations and improvements in professional staffing, the suit has had impacts in the following areas:

- Increase in the number of clients served by educational and pre-release programs at the institution;
- Increase in the quality of educational and pre-release programs at the institution;
- Increase in the number of released clients followed up by the institution on a regular basis;
- Increase in the number of clients receiving services in the community; and,
- Increase in the number of clients placed in group homes in the community.

The Superintendent of Belchertown stresses, however, that this suit did not cause the institution to change. Rather, the suit and its continuing settlement have been instrumental in allowing the staff at Belchertown to make desired changes in their programs and facilities which they previously did not have the means to implement. The suit and other changes are viewed by the administration not as ends in themselves, but rather as means for the institution to move in directions toward which they themselves have been striving.

## 2.0 CLIENT ASSESSMENT PROCEDURES

In 1972, client assessments were conducted on an individual basis by a multidisciplinary team; evaluations became much more comprehensive in 1973 and 1974. According to staff, all clients released in 1972 received medical and psychological assessments annually, and social assessments bi-annually; the majority also received annual educational and vocational assessments. Clients released in 1973 and 1974 received annual assessments only; all were assessed in the medical, educational, vocational and social areas. Half of the clients released in 1973, and 80% of those released in 1974, received annual psychological assessments.

Over the three-year period, the same staff categories participated in the assessments. These staff included the Superintendent of Belchertown, unit directors, physicians, psychologists, social workers, nurses and direct care staff. When appropriate, vocational rehabilitation counselors, educators, speech and physical therapists, and volunteers participated in assessments as well.

According to staff, clients released over the three-year period discussed their assessment results with staff. Families, guardians, and advocates of clients were also invited to participate in assessments; in 1972, 31% participated, in 1973 40% participated, and in 1974 65% participated in assessments. Other outside persons who were invited to participate in assessments of clients included physicians, legal assistants, and regional and state representatives from the Department of Mental Health and representatives from other concerned agencies.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction

The Belchertown State School has a total of four pre-release programs for adults, including a Rehabilitation Unit Program, the Carval Workshop, the Day Work Program, and a Pre-Vocational Workshop. Clients released during 1972-1974 did not participate in this last program; the following discussion will therefore be limited to the first three pre-release programs. There is also a program in community skills for children from 6 to 12 years of age, but no target clients participated in this program.

### 3.2 Program Descriptions

#### 3.2.1 Residential Rehabilitation Program

The purpose of the Residential Rehabilitation Program as described by Belchertown staff, is to develop each resident to her/his fullest potential by means of individually appropriate and non-restrictive programs. Clients live in cottages on the Belchertown campus, and are taught how to care for their own room and possessions, how to go shopping, etc.

On a typical day in the program, clients awaken, dress themselves, and have breakfast. Emphasis during these activities is placed on personal hygiene, good grooming, and proper eating skills. After breakfast, clients leave for work, with some taking public transportation. Some of the residents work in sheltered workshops, others in competitive employment. When clients return to the institution from work, they eat supper and then participate in a variety of activities, including night school and recreation programs. Some of the types of activities incorporated into the Residential Rehabilitation Program include speech stimulation, job preparation and work habit improvement, training in personal responsibility, and sex education.

Approximately 80% of the target clients released in 1972-1974 participated in the Residential Rehabilitation Program. Clients are referred to the program by multi-disciplinary teams as a rule, although some clients enter the program through self-referral. The types of skill training provided in the program did not vary greatly from 1972-1974. Staff report that all clients received training in decision-making, and in advanced personal hygiene skills such as choosing clothing. The majority of clients -- from

65% to 85% -- also received training in housekeeping, behavior management, birth control and other forms of sex education, academics, use of community resources, use of public transportation, money management, preparation for job applications and interviews, and specific job skills. Staff involved in the program (ranked from first to last according to the amount of time spent with clients) included the following: direct care staff, social workers, vocational rehabilitation counselors, psychologists, unit directors, physicians, educators, and speech therapists. Volunteers from the community also participated.

### 3.2.2 The Carval Workshop

The Carval Workshop is described by staff as a sheltered workshop intended to develop residents' job skills and interpersonal relationships to their fullest potential through individual programming in an unrestricted environment.

During a typical day in the program, clients arrive at 8:15 a.m., check in at their work station, and do work subcontracted by various local industries. In addition to job skills, emphasis during the day is placed on work habits and personal hygiene habits. The work day ends at 4:15 p.m.

Participation in the program by clients released over the three-year period increased substantially: in 1972, a little over 20% of the released target clients had been involved in the Carval Workshop program; almost half of those released in 1973 participated; and 70% of those target clients released in 1974 participated in the program. When places were available, clients are admitted to the program through interdisciplinary team referral; referrals are based primarily on clients' readiness and potential.

Staff report that all target clients released from 1972-1974 who participated in the Carval Workshop received training in the same skill areas. These included: personal hygiene, behavior management, sex education, pre-academics, money management, and specific job skills. The following staff, ranked according to the amount of time spent with clients, were involved in the program: vocational rehabilitation counselors, instructors, direct care staff, and social workers.

### 3.2.3 The Day Work Program

The goals of the Day Work Program as described by staff are to train clients in specific job skills, and to enable them to attain the social and behavioral skills necessary for living in the community, by offering them day work in the local community. A typical day in the Day Work Program is much the same as one in the Residential Rehabilitation Program described above. In the Day Work Program, residents go off the campus for their competitive employment or for jobs in sheltered workshops in the community. In addition to the actual jobs, the program offers clients training in related community skills, using the local community as the actual "training ground." For example, residents learn about banks, post offices, public transportation, traffic rules, etc. by going out and using these facilities/ regulations in the community.

Between 10% and 20% of the target clients released in 1972 and 1973 had participated in the Day Work Program; half of those released in 1974 had participated. There are no specific criteria for admission to the program. All clients referred in 1972, 1973, and 1974 who participated in the program reportedly received training in the same skill areas. These included: personal hygiene, behavior management, sex education, academics, use of community resources, money management, preparation for job applications and interviews, and specific job skills. The following staff, ranked according to the amount of time spent with clients, were involved in the Day Work Program: vocational rehabilitation counselors, instructors, direct care staff, unit directors, and social workers.

### 3.3 Sequence of Pre-Release Programs

Generally, clients live in the Residential Program and during the day participate in the Carval Workshop. When they are ready for a community job, they then enter the Day Work Program.

### 3.4 Overall Characteristics of Pre-Release Programs

Staff at the institution cited a number of strengths of the pre-release programs currently operating at the institution. For example, clients are given the option as to which type of program they prefer, as well as where and with whom they will live; this allows them considerable practical training in the area of decision-making relevant to their lives. Other strengths noted in the programs include the use of the community as a training ground for clients, and the fact that the institution's administration gives very strong support to clients in the programs.

Weaknesses in the pre-release programs were seen to include a lack of cooking facilities for training in meal preparation, somewhat institutionalized living arrangements, and a lack of funds for client transportation and leisure-time activities. It is hoped that the renovations currently being implemented at the Belchertown State School will help to resolve the first two problems. These renovations have been made possible by funds allocated by the class action suit (see Section 1.2.3) and by Title 19 (Social Security Act) monies.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

As described in Section 2.0, a multi-disciplinary staff team meets with the client to determine whether the client is ready for community placement. This meeting may be initiated by the client. Once the team and the client have decided that a community placement is appropriate, they meet with various community resource persons to determine if an actual placement exists in the community. Persons contacted at this time include the client's family, representatives of rehabilitation agencies and community residences.

A number of criteria figure in the decision to place a client in the community. First, there must be a desire for placement on the part of the client and her/his family if the client is under 18 years of age. Staff must also consider the client able to benefit from placement, and there must be continuing support services available in the community into which the client is placed.

### 4.2 Factors Affecting Release

According to staff at the institution, clients who are easiest to place in the community possess the following characteristics:

- high functioning self-help skills;
- good interpersonal skills;
- good health;
- high potential for personal growth; and
- high motivation for work and placement.

In short, the clients easiest to place are those who are least handicapped and least in need of supportive services. They are generally non-aggressive, docile persons who do not "stand out" from the general population.

The most difficult clients to place are described by staff as persons who have:

- severe acting-out behaviors;
- poor self-help skills; and
- an inability to fit into existing programs.

These clients are ones who don't "fade into" society easily. Often, they may be more capable than other clients in terms of adaptive skills (e.g., they may be better at manipulating their environment), but they are not as acceptable to society because they act out their differences more often. Thus, the clients most difficult to place in residences, jobs and/or schools are those whom society is least able to tolerate. In fact, one staff member cited physical attractiveness as a crucial placement factor. A client whose appearance and expressions are physically unattractive is often more difficult to place in the community than one with a low functioning level.

The type of setting in which a client is placed depends primarily on the ability of the setting to meet the client's individual needs. For example, placement in the client's natural home depends not so much on age or level of handicap, but rather on family interest and ability to care for the released client. Adoptive and foster homes generally take in younger residents with self-help skills. The typical resident in a group home generally has self-help skills and the ability to take advantage of day programs in the community. Residents in semi-independent and independent living situations are usually ones who have "graduated" from previously living in a group home in the community.

Staff feel that there are certain characteristics which may lead to a client's eventual placement in a particular type of living situation. For example, younger residents with high self-help skills are usually placed in adoptive or foster homes, while residents of any age, who have self-help skills and also an ability to take advantage of existing day programs in the community, usually go to group homes. Adults of any age may go into semi-independent or independent living situations, usually after "graduation" from a group home. Placement with a client's natural family usually depends more on the interest and abilities of family members, rather than on the client's own abilities.

## 4.3 Client Status Upon Release

Staff at Belchertown report that the fact alone that an individual resides at the institution has no effect on her/his legal powers to marry, enter into employment contracts, secure legal services, leave the facility, or refuse medical and other services offered by the facility. Once the client has been placed in the community, there are no limiting factors on her/his rights.*

For clients released in 1972-1974, the large majority of releases were institution-initiated (as opposed to family-initiated). In most cases, clients were released on extended visit, rather than formally discharged. Clients released on extended visit status could return voluntarily to the institution after any time span, without regard to waiting lists or waiting periods. The institution cannot, however, return a client involuntarily once she/he has been released.

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*As a result of a court suit which challenged the restriction on the residents' right to vote, the law was changed to add this constitutional right to the residents' legal powers and several residents are now registered voters.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

According to Belchertown staff, clients released from the institution are followed up on a monthly basis primarily by social workers from the regional mental retardation authority. The State School, however, does retain some responsibility for follow-up of its released clients, regardless of the type of release (i.e., extended visit or discharge). Each client is assigned to a social worker or other appropriate staff member at the State School. Procedures for follow-up by the State School include letters, phone calls, and/or visits to the clients' work or home setting. In addition, clients often return to the State School grounds to visit friends of staff and to attend movies or parties held at the School on the weekends.

### 5.2 Support Services Provided to Clients

#### 5.2.1 Agencies with Continuing Responsibility for Client's Welfare

The two agencies who retain continuing responsibility for a client's welfare once she/he leaves the institution are the Belchertown State School and the regional mental retardation authority. The institution may provide medical, dental, and social services, as well as recreation programs, vocational programs and respite care. Depending on various eligibility criteria, private or public programs apart from the institution may provide these services, as well as legal and educational services.

#### 5.2.2 Types of Support Services Provided to Clients

Staff report that all clients released from 1972-1974 received social and medical services. The large majority of those released in 1972, and all those released in 1973 and 1974 also participated in recreational programs. Over the three-year period, approximately 80% participated in vocational training, and 20% in educational programs. Medical care was provided to these clients annually, and educational, vocational and recreational programs occurred on a weekly basis. Social services were provided monthly in 1972 and 1973, and on an as-needed basis in 1974. In most cases, social services and medical care were provided by the institution, while the remaining services were provided by community agencies such as public schools and local sheltered workshops. Beginning in 1974 most of these services are received within the community framework.

## 5.3 Support Services Provided to Those Responsible for Released Clients

According to Belchertown staff, all the "families" of clients released over the three-year period received training to facilitate their interaction with clients. Natural families usually received social service counseling and foster families received training in behavior modification and foster care techniques. Group homes received training by a regional Department of Mental Health Community outreach team including training for housemanagers and training in behavior adjustment.

The teachers and employers of clients released during the three years also received support from the institution. For example, institution staff discussed individual released clients with school officials and special education program personnel in the schools. Vocational rehabilitation counselors or unit directors from Belchertown visited employers on a weekly basis until the employers felt comfortable with clients.

## 5.4 Institution's Assessment of Released Clients' Adjustment to Community Living

Belchertown staff have attempted to assess the community adjustment of released clients through client conferences, houseparent conferences, and contacts with the employers of released clients. The Superintendent of the State School estimates that 10% of the target clients are adjusting fairly well, 10% are adjusting moderately well, and 80% are adjusting extremely well. According to the Superintendent, the clients who have made the best adjustment are those who should never have been institutionalized in the first place. They tend to be self-motivated individuals who are anxious to succeed in the community.

Clients with behavior problems and who have been institutionalized for long periods tend to have the most difficulty in adjusting to living in the community. These are persons who lack confidence, a sense of belonging to a social group, and a sense of being productive, all of which, staff feel, are elements crucial to existing in and feeling a part of one's community.

## 6.0 RELEASED CLIENT PROFILE

As noted in Section 1.0, released clients between 1972-1974 were grouped into two categories: "target" and "non-target" clients (see Glossary for definitions). Information on the released population will be presented first for the entire group, and secondly, for target and non-target clients separately. Since the focus of this study was on the target population, more information was collected for this group.

Belchertown State School released a total of 273 residents between 1972 and 1974. The largest group was released in 1972 when 126 residents were communitized, representing 12% of the total institutional population for that year. In 1973, another 85 residents were placed into the community, representing almost 9% of the institutional population for that year. Finally, in 1974, Belchertown released 62 clients (or 7% of the institutional population). The large majority of clients released were between the ages of 19 and 40 years. Males accounted for 60% of the 1972 releases, while females constituted a little over half of the 1973 and 1974 releases.

Nearly a quarter of the released residents during this period were either mildly retarded (24%) or severely retarded (23%). Moderately retarded were the most numerous, accounting for 39% of the entire released population. Approximately 14% of those released were classified as profoundly retarded.

Of the entire released population, 50% were placed in group homes. The next most common placement was to nursing homes, where 27% of the overall released population was placed. Natural/adoptive homes received 8% of the communitized group, while foster homes received 4% of those released. Eight percent of the released group was placed in other institutional facilities, while only 3% were placed in independently living situations.

Of those clients released in 1972, 1973, and o974, a small majority had originally been committed to Belchertown through authorization of a parent or guardian; the remainder had come to the institution as a result of court commitment.

## 6.1 Characteristics of Target and Non-Target Clients

Of the total 273 clients released between 1972 and 1974, 120 are considered target clients for this study. Of these target clients, 45 were released in both 1972 and 1973, while in 1974, 30 target clients were communitized. These clients represent 4% of the institutional population in 1972, 5% in 1973, and 3% in 1974. About 15% were between the ages of 6 and 18 years and the remainder were aged 19 or older. While in 1972 and 1973 the slight majority of released target clients were male, in 1974, 57% of the target clients were female.

A total of 153 non-target clients were also released during this period. In 1972, 81 non-target clients were communitized, representing 8% of the total institutional population of that year. In 1973, less than half that number, or 40 clients were released (4% of the institutional population). Finally, in 1974, 32 non-target clients were released, representing another 4% of the institution's enrollment. Nearly all these clients (93%) were aged 19 or over, and the majority of those released were female for all three years except 1972, when the slight majority were male.

Of the children and youth in the target population, nearly half (43%) were mildly retarded. The overall distribution of residents by level of retardation for the target group was as follows: 28% mildly retarded, 40% moderately retarded, 21% severely retarded, and 11% profoundly retarded. The non-target population's distribution by level of retardation did not vary markedly from the target group: 20% were mildly retarded, 38% moderately retarded, 25% severely retarded, and 18% profoundly retarded.

The most common additional handicapping conditions among the target population (other than mental retardation), were speech problems, cardiac problems, and mobility limitations. For the non-target group, severe hearing impairments affected approximately 10% of those released; mobility limitations and blindness were also reported to be additional handicaps of this group.

## 6.2 Skills of Target and Non-Target Clients Upon Release

Information on the skills training of released clients was obtained only for the target clients. According to staff, of these clients who were released from 1972-1974, 95% possessed self-help skills, and the large majority -- from 90% to 93% -- also possessed skills in personal hygiene, housekeeping, behavior management, and in pre-academic skills such as the identification of shapes, colors, numbers, etc. Large numbers of target clients also possessed knowledge or skills in the areas of birth control and human sexuality, academics, use of community resources, use of public transportation, money management, preparation of job applications/interviews, and specific job skills. Less than half of the target clients released during these three years had skills in the area of meal preparation.

## 6.3 Residential and Day Placements of Target and Non-Target Clients

Of the children and youth included in the target population, well over half were placed in group homes (57%). Nearly a quarter were placed in their natural/adoptive homes, while 19% were placed in foster homes. The adult population in the target group was also most frequently placed in group homes (82%). Less than 10 were returned to their natural/adoptive homes, 6% went to foster homes, and 5% were placed in independently living situations. Taking the target group as a whole, nearly 80% of the target population was placed in group homes, 10% in natural/adoptive homes, 8% in foster homes, and 4% in independently living situations.

Placements for the non-target population were most frequently nursing homes where 52% were placed. About 15% of the non-target group were placed in other institutions. Of those who were released to community residential settings besides nursing homes or other institutional facilities, 22% were released to group homes, 8% to natural/adoptive homes, and 3% to independently living situations.

Staff from Belchertown report that during all three years, clients visited their residential settings prior to release.

In 1972, half of the released target clients went to full-time competitive employment for their day placements, and a little less than one-third went to workshop placements. Relatively small numbers of target clients released in that year went to part-time competitive employment and to public school programs. Workshop placement was the most common type of day placement in 1973, with over half of the released clients going into this type of community setting. Day activity centers were the next most frequent type of placement, followed by full-time competitive employment.

Relatively small numbers of clients went into public school programs. In 1974, the most frequent type of placement -- for approximately 70% of released target clients -- was to workshops. The next most frequent type of placement was to day activity centers, followed by public school programs and full-time competitive employment.

Over the three years, clients were most frequently released to workshops as day placements, followed by full-time competitive employment, followed by part-time competitive employment, public school programs, and day activity centers. In all three years, staff report that all clients released into the community had visited their prospective day placement within the six months prior to release.

Information on the day placements of the non-target released population was not gathered.

### 6.4 Readmissions

Approximately 10% of the target clients released in 1972, 1973, and 1974 were subsequently readmitted to the institution. The majority of clients released in the first two years and then readmitted were males, while the majority of readmissions from 1974 releases were females. For all three years, the majority of readmissions were adults between the ages of 19 and 40. Most returnees had been in the community for less than six months at the time of readmission, although a few stayed for as long as six months to three years.

For all three years, readmissions came most frequently from group home settings; other original placements for readmitted clients were natural and foster homes. In all cases, readmitted clients had been on extended visit status when released. The most common stated reason for readmission was "poor adjustment," which included such problems as lack of a job, incompatability with employers, and lonesomeness on the part of the client. Medical problems and poor adjustment on the part of foster parents were also cited as reasons for readmission.

Readmission figures and causes for non-target clients were not obtained.

## 7.0 PROFILE OF STUDY GROUP CLIENTS

Of the 120 target clients released from Belchertown State School during 1972 and 1974, 44 or 37% were interviewed during July and August of 1975 and are referred to as the study group (see Glossary). In addition, two released clients who subsequently returned to Belchertown were interviewed at the institution. In this section information gathered from institutional staff, records, the study group member, his/her family, housemanager, social worker, or other contact person from the community who was interviewed about the study group member will be presented. The information is not intended to serve as a validation of the information gathered from the institution about training, services, or follow-up provided to released clients, nor is it intended to be a "follow-up" of the released clients. Rather, it provides another view of the deinstitutionalization process. The descriptive information will be presented on the types of clients interviewed from Belchertown as well as the study groups' perceptions of their problems since release. In addition, information will be presented from the families of the released clients on the institutional follow-up, the types of services received, and the types of problems encountered since release.

### 7.1 Study Group Characteristics

There was a range in ages of the study group released from Belchertown from 10 to 51 years and an average of 28 years. The vast majority (90%) were white. Over a third of the study group (39%) were moderately retarded, a quarter were mildly retarded, 18% severely retarded, 9% profoundly retarded, and about 10% had no specified level of retardation recorded. The most common additional handicaps other than mental retardation were speech impediments (25%), psychological problems (20%), and mobility limitations (9%).

## 7.2 Residential and Day Placements

### 7.2.1 Residential Placements

The most common initial residential placement for the study group clients released from Belchertown during the 1972-1974 period was to group homes (80%). Current residential placements were also most commonly group homes (79%). While foster homes initially received 9% of the study group, none of the study group members were living in foster homes at the time of the interviews. About 5% of the study group were initially placed in natural/adoptive homes and a similar proportion were living in such settings when interviewed. Another 7% initially were placed in unspecified community residences. Current placements showed 14% of the study group living independently and 2% living in semi-independent settings.

### 7.2.2 Day Placements

According to the families or contact person of the study group, the most common initial day placement was in competitive employment situations (41%). Over a quarter initially were placed in sheltered workshops upon release from Belchertown and about a quarter went to a school program (23%). About 5% were placed in a day activity center and the remaining 5% went to other types of placement. One study group member was not initially placed in any day program.

At the time of the interviews, over a third (36%) had changed their day placements from their original program or activity. Half the study group was at the time of the interviews involved in a competitive employment or sheltered workshop program. Another third (32%) were in a school program and a third (34%) were in a day activity program.* A little over 10% of the study group reported that they were not involved in any day program at the time of the interview. The most common reason given for the lack of a day placement was that the study group member was reluctant to participate in a day program. Other reasons given were that there were no appropriate programs or that the client was dropped from a program because she/he could not keep up with the demands of the program.

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*Multiple day placements were possible so that the percentages cited exceed 100%.

## 7.3 Institutional Follow-Up and Study Group Clients

Families of the study group clients were asked if anyone from the institution had follow-up contact with the client after release. Approximately 75% of the respondents reported that there was some follow-up from an institutional staff member. The most frequently stated method of contact was by visitation to the client's residence. Other methods of follow-up were by phone conversations and by contact through the client's community social worker or someone responsible for the client.

The amount of follow-up contact seemed to decrease over time. Whereas contacts during the first six months after release were reported by 75% of the respondents, during the six months immediately prior to the interview, only half of the respondents reported any follow-up. However, the frequency of the follow-up seemed to increase over time. For those respondents who said they were contacted by institutional staff during the first six months after the client's release, they reportedly occurred most often only twice a year. For the most recent six months, those receiving some follow-up contact reported that it was most often on a monthly basis.

Family respondents were asked how satisfied they were with the amount of follow-up provided by Belchertown. About 40% of those who responded said that they were very satisfied with the follow-up received. Less than a quarter of the respondents (21%) said they were dissatisfied, while the remaining respondents said they were neither satisfied nor dissatisfied with the amount of institutional follow-up.

## 7.4 Case Managers and Study Group Clients

Nearly all the study group members (98%) reportedly had a case manager, or someone who was responsible for the client's well-being and for on-going support. For the vast majority of these clients, the person cited as casemanager was the parent, or in group homes, the houseparent. Thus, when the frequency of contact of the client with the case manager was asked, nearly all the respondents answered that they were in daily contact with their case manager.

## 7.5 Services and Training

### 7.5.1 Service and Training Needs

Family respondents were asked about support services and training needs of the released study group.* The support services cited by the respondents most often as needed and not received by the released study group from Belchertown were dental services, social and/or psychological counseling, and speech therapy. The types of training cited as needed but not received by the study group were most frequently the use of social and community agencies (cited by nearly a quarter of the respondents), reading and writing, the use of numbers, and language skills.

The support services most frequently mentioned by the respondents which they felt they needed but did not receive were support and/or training prior to the client's coming to the residence (cited by over a third of the respondents). Over a quarter cited parent or professional associations as a service which was needed but not received.

### 7.5.2 Service and Training Use

Family respondents were asked about the client's use of various support services and about the client's training in various skill areas. Out of the eleven possible services mentioned, the study group from Belchertown used an average of six services since release. The average number of skill areas in which Belchertown's released study group received training was 13.

Family respondents were also asked about the providers of the services and training received by the study group. Of the support services used by the study group, respondents reported that over a quarter (28%) were received from the community residence in which the study group member was living and a similar proportion (28%) were received from a community agency. A little less than a quarter (23%) of the services received were from the released client's day program while other sources provided 18% of the services used. Belchertown reportedly provided 3% of the services received.

Of the training received by Belchertown's released study group, two-thirds were reportedly provided by the community residence. About a quarter (26%) were provided by the client's day program while 7% were provided by a community agency. Respondents cited Belchertown as the providers for 3% of the training received since release.

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* See Glossary for a list of the services and training on which information was collected.

## 7.6 Problems

Respondents were asked a series of questions about the types and degree of severity of various possible problem areas for the study group. The most commonly cited problems of the greatest severity were family and social relationships, medical problems, and loneliness. Other problems cited of a lesser degree in severity were behavior problems, keeping a job, and personal grooming habits.

Study group members were also asked which problems they considered to be the most difficult since leaving the institution. The majority of the clients cited finding a job as a major problem. Other problems mentioned included budgeting money, social relationships, and psychological problems.

## 7.7 Interviewer's Perceptions of Study Group Adjustment

Following each session, interviewers recorded their perceptions about the study group member's adjustment to the community along three dimensions: degree of social isolation, client satisfaction/happiness with his/her life in the community, and the overall adjustment of the client to the community.

Nearly 75% of the study group members were perceived as having some or many social relationships in the community. Only 5% of Belchertown's released study group were perceived as being very socially isolated, another 14% were perceived as being somewhat socially isolated. For the remaining 6% of the study group, the interviewers felt unable to judge the degree of social isolation.

Over half (55%) of the study group were perceived as being happy or contented with their lives in the community. About 19% were perceived as somewhat happy with their current life while 17% were seen as either somewhat or very unhappy in the community. Interviewers were unable to judge client's happiness for 9% of the study group.

Finally, the study group's overall adjustment to the community was judged by interviewers. About half (52%) were judged to be well adjusted to life in the community. About a third (36%) were seen as somewhat adjusted while none of Belchertown's released population were perceived as poorly adjusted to community life. Interviewers were unable to judge the community adjustment for 11% of the released study group.

# CHAPTER 5.0: BRAINERD STATE HOSPITAL

## 1.0 INTRODUCTION

### 1.1 Overview

Brainerd State Hospital, one of 10 regional facilities in Minnesota, serves (as of the fall of 1975) 556 mentally retarded, mentally ill, and chemically dependent (alcoholic and drug dependent) persons. The facility, opened in 1958 under the state's Department of Public Welfare, initially served only mentally retarded clients. In 1971, as part of the state's efforts to regionalize services, Brainerd became the first facility in the state to develop multi-services for the mentally ill and chemically dependent as well as the mentally retarded. The development of services at the facility for all types of disabled persons was intended to enable clients to remain closer to their own communities and families.

As of July 1, 1974, Brainerd became one of seven state facilities in the United States to receive full accreditation in both their psychiatric and mentally retarded programs from the Joint Commission on Accreditation of Hospitals. Approximately 80% of the total residential population at Brainerd is mentally retarded. Of the mentally retarded clients at the facility, 85% are severely or profoundly retarded. The vast majority of mildly and moderately retarded clients who were previously served by the facility have been placed in community settings during recent years, according to staff. The only higher level functioning clients currently at the facility are those with severe behavior problems; many have been repeatedly placed in community settings but have subsequently returned to Brainerd because of poor adjustment.

As a result of the deinstitutionalization of higher functioning mentally retarded persons, the total institutional population was reduced by 23% between 1972-1974, from 729 residents in 1972 to 558 in 1974. There was a reduction in population of only 2 residents between 1974 and 1975, which suggests that most of those residents who could be placed in community settings have now been released. Females have constituted about 46% of the total population both during the period under study and in 1975. The age range of Brainerd's residents has remained stable for these years with a consistent 27% of the population aged 18 or under and 73% aged 19 or over. The levels of retardation among Brainerd residents has not shown noticeable variation during either the period under study or during 1975. The largest group (60%) of the population is classified as profoundly retarded. Severely retarded residents are the next largest group, comprising one-quarter of Brainerd's residents since 1972. Moderately retarded clients have accounted for 8% of the population and mildly retarded residents have accounted for 7% of the population both during the 1972-1974 period and for 1975.

The types and frequency of additional handicapping conditions other than mental retardation experienced by Brainerd residents has also remained fairly constant. Approximately 36% of Brainerd's population had multiple additional handicaps during the period under study. The most common additional handicap was epilepsy, affecting 38% of the population. The 1975 residential population did not differ from the residents at Brainerd during the period under study in terms of additional handicapping conditions. Staff report that after epilepsy, the next most common handicapping condition of the 1975 population was mobility limitation, experienced by approximately 29% of the residents.

Residents at Brainerd are mostly court committed. Eighty-three percent of the residents residing at Brainerd during the period under study and currently were admitted through court action. The remaining 17% entered through either self-admission or parental or guardian authorization.

Per capita expenditures increased by 44% between 1972 and 1974. In 1972, per capita expenditures were put at $6,594. By 1974, this figure had risen to $9,483. Current per capita expenditures were put at $11,708, representing a 23% increase from 1974. Staff distribution did not show any marked increases or decreases in the period under study. Recent staffing patterns show the greatest concentration in the attendant category position, which constitutes 30% of the reported 725 staff members in 1975. Between 1972 and 1974, the staff increased by 6%, from 684 to 724 staff, with increases primarily evidenced in the number of support staff and teachers. Brainerd State School participates in a program which utilizes public school staff and teachers for the teaching of its residents.

## 1.2 State Context

### 1.2.1. State and Institution Deinstitutionalization Policies

The goal of the state's deinstitutionalization policy is to place clients in settings as close as possible to their home communities and families. This policy has evolved during the past 5 years as the state has moved toward a new plan for mental health care--regional services for disabled citizens. Within this broad movement to consolidate services into regional care systems, there have been several other major events which have helped to shape the state's deinstitutionalization policy:

- The passage in 1972 of regulations by the State Department of Public Welfare which established uniform rules, regulations, and program standards for all facilities (both institutional and community based) serving 4 or more mentally retarded residents. All programs must be licensed according to these standards in order to receive state funds. The standards cover areas such as physical plant, developmental and remedial services, admission and release procedures, and administrative policies and practices. These standards, according to staff, have helped to upgrade both the community and institutional services for the mentally retarded.

- The passage in 1975 of the Mental Retardation Protection Act provides a coordinated approach to the supervision, protection, and habilitation of mentally retarded persons. There are several aspects of this law which relate to deinstitutionalization:

  (1) It places limitations on the involuntary commitment of mentally retarded persons;

  (2) Introduces the concepts of limited guardianship and periodic review of guardianship status;

  (3) Provides safeguards for sterilization procedures for mentally retarded persons; and,

  (4) Repeals a state law which "on the books" prohibited the marriages of mentally retarded or mentally ill persons.

## 1.3 State Legislation Relating to Deinstitutionalization

### 1.3.1 The Right to Education Law and Its Impacts

There are three state laws which relate directly to the education of handicapped children. Prior to 1971, the only state law in effect was the Educable Training Act which required that local school districts provide an education for all mentally retarded children within the "educable" range (defined as IQ 50 or above) and permitted school districts to provide education for "trainable" mentally retarded persons (IQ 0-50). "Trainable" mentally retarded children were not guaranteed public education by local school districts until 1971 when the Mandatory Trainable Act was passed. According to this law, school districts must provide trainable as well as educable classes for mentally retarded children between ages 5 and 21 within their borders. The local school districts are responsible for paying for the education of these children, regardless of where the person receives the schooling. All teachers in these classes must be certified in special education according to this law, which was fully implemented at Brainerd by 1972.

The third state law which relates to the education of handicapped children is the Permissive Education Act which permits local school districts to provide public education to mentally retarded persons between the ages of 21 and 26. According to staff at Brainerd, this Permissive Education Act may eventually become mandatory, as the concept of education for mentally retarded citizens broadens.

These laws, according to staff at Brainerd, have had major impacts on the facility's programs and policies. Most significant has been the increase of clients at the facility participating in full time educational programs. Two hundred and thirty clients at Brainerd State Hospital were involved previously in educational programs but were provided with more complete curriculum once the Mandatory Trainable Law was passed in 1971. In the overwhelming majority of cases, clients at Brainerd receive their education in classes held on the ground of the facility. In fact, a few mentally retarded children from neighboring communities attend these classes at the institution because appropriate programs are not available in their home districts.

The number of teaching staff at the institution has increased due to the passage of these laws. Before the passage of the Mandatory Training Act, there were 14 school teachers in the Brainerd State Hospital school program. Now there are 80 public school teaching staff, with a teacher: student ratio of about 1:3.4. Implementation of these education laws has helped the institution to meet many state and federal licensing standards which require educational programming and specified staff: resident ratios, such as the state's Department of Public Welfare ruling and the federal ICFMR* regulations. Also, these laws have spurred the development by staff of new educational measurements and assessment devices to evaluate the progress of mentally retarded residents.

The passage of these laws has also resulted in more clients being released from Brainerd State Hospital into local communities as school districts have begun to develop special education programs for these citizens. Another impact of these laws, cited by Brainerd staff, has been the growth of teacher training programs in trainable mental retardation at local and state colleges. More teachers have entered this field as the education of trainable mentally retarded persons (IQ 0-50) has become a priority in the state.

### 1.3.2. The Periodic Review Law and Its Impacts

The state legislature passed a law in May, 1971 and the state's Department of Public Welfare issued regulations in November, 1972 pertaining to the periodic review of mentally retarded residents in state facilities. Basically, the law and the regulations require that facility staff participate in ". . . regular--at least annual--assessments of each resident, conducted by an inter-disciplinary team . . ." Brainerd State Hospital was in full compliance with these laws by 1972. In fact, at the time this legislation was passed, the facility was already conducting and continues to conduct quarterly reviews (every 90 days) on each resident. Staff at Brainerd feel that the overall periodic review process has resulted in more clients participating in educational and pre-release programs and more clients being released from the institution into community settings.

## 1.4 State Litigation Relating to Deinstitutionalization and Its Impacts

In 1974, a suit was brought against the Commissioner of Public Welfare, the Chief Executive Officer, et al. by a mentally retarded resident of another state facility charging involuntary confinement without treatment. A judgment was entered on October 1, 1974 by the court, mandating that the Commissioner of Public Welfare request funds to upgrade the physical facility, specifying direct care staff: resident ratios, and requiring the development of individual habilitation plans and annual evaluations of each resident's eligibility for community placement. Although the judgment was entered in 1974, all of the resources necessary to carry out the judgment have not been appropriated by the legislature which has maintained that of the limited funds, more should be spent on community programs, rather than meeting all the requirements of the court order. Because the court-ordered improvements have not been made, the suit was brought back to court in June, 1975. The plaintiffs argue that the court should require federal monies to be allocated directly to the state facility for improvements, rather than to the state general fund. According to staff at Brainerd State Hospital, the indirect impacts of this suit on their facility have been twofold: (1) a minor increase in staff; and (2) a feeling of frustration in trying to meet everyone's expectations, i.e., improvement of the institution.

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*Regulations for federal reimbursement, under the Title 19 (Medicaide) of the Social Security Act, for Intermediate Care Facilities for the Mentally Retarded, (ICFMR).

## 2.0 CLIENT ASSESSMENT PROCEDURES

There are several types of procedures used at Brainerd State Hospital to assess the needs and progress of residents. During the 1972-1974 period, the American Association on Mental Deficiency's Adaptive Behavior Scale (ABS) and a Division of Vocational Rehabilitation evaluation was done on every client. In addition to these scales, staff at Brainerd have developed two of their own assessment devices:

(1) Brainerd Rating Scale--a behavior checklist of 80 items which supplements the ABS, covering various self-help areas; and

(2) Feeding Training Scale--a detailed scale on feeding and table manners which is used to assess progress in these areas. Several units at Brainerd now operate on an Integrated Feeding Program in which staff eat family style with residents. Based on these communal meal experiences, staff can determine the specific training needs of individual clients in the areas of self-feeding and table manners.

Psychological and vocational assessments were conducted on all clients every two years; medical, educational, and social assessments were done annually. All of these assessments were reviewed quarterly (every 90 days) by an interdisciplinary staff team to determine the progress of the clients or changes in their conditions. The following staff regularly participated in the assessment of clients during the 1972-1974 period: Unit Director, psychologist, social worker, nurse, direct care staff, educators, speech therapist, physical therapist, and volunteers. Physicians participate on an as-needed basis.

Since 1973, families, guardians, and advocates of clients have been formally invited to participate in these regular assessments. About 15% of clients' families in fact participated in 1972 and 1973. The participation rate increased to about 30% in 1974. According to staff, all families, guardians, and advocates receive a written report on these regular assessments. The written report is interpreted or explained to each family by staff at the institution or staff from the County Welfare Department.

In addition to inviting families, representatives of the County Welfare Department, local schools, and mental health centers are invited to take part in client assessments. Staff at Brainerd also stated that all of the clients themselves were involved in these assessments including the review and discussion of their assessment results with staff.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction

Brainerd State Hospital has one residential pre-release program for children--Unit 2-3, and two pre-release programs for adults: the Cooperative Vocational Rehabilitation Program (CVRP) and Program 6. All of these programs were available to clients released during the 1972-1974 period.

### 3.2 Program Descriptions

#### 3.2.1 Unit 2-3

About 20% of the 140 released target clients* during 1972-1974 participated in Unit 2-3, a short-term treatment program for children aged 5-21, which aims to correct each client's functional, behavioral, and/or medical weaknesses which prevent him/her from living in the community. The overall goal of the program is to assist every client in achieving the maximum independence in functioning as her/his potential allows.

On a typical day in Unit 2-3, children awake at 6 a.m. and participate in dressing and toileting activities. Breakfast is at 7 a.m., more bathing, toileting and grooming continues after breakfast until 9. From 9-11 a.m., children are involved in the school program at Brainerd, speech and physical therapy and activities with Foster Grandparents (A Federal program under the Action Office). Children return to Unit 2-3 for lunch, after which there is leisure time and then more school programs, therapy, and foster grandparent activities. At 5 p.m., supper is held. After dinner, children participate in playtime, recreation, and bathtime activities until bedtime at 9 p.m. All of the children in the program are involved in school program 5-6 hours per day. They also participate in many field trips and camping experiences in the community.

All of the clients in this Unit received training in self-help skills, personal hygiene and pre-academics. Training in housekeeping and meal preparation was provided to about 3/4 of the clients in this program; training in behavior management and in academic skills were provided to about one-half of the clients. Approximately 10% of the clients in Unit

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*See Section 6.0 for a description of the target clients released .

2-3 received training in sex education, use of community resources, and money management.

According to staff, a variety of techniques have been used to teach in these training areas, with repetition of training being the most important ingredient. In the area of self-feeding, children are given special spoons and dishes to assist them in eating independently. A specific toilet training program on a scheduled basis has been utilized for most of the children--only a few are completely trained. In the area of grooming, most of the children are started on toothbrushing and hairbrushing by just grasping the brush. Once they have mastered this step, they move on to the other tasks in the sequence until they can brush completely by themselves.

The primary staff involved in Unit 2-3 during the 1972-1974 period were direct care staff (Human Service Technicians), volunteers, teachers and teacher aides, nurses and social workers.

### 3.2.2 Cooperative Vocational Rehabilitation Program (CVRP)

CVRP, a residential program for adult clients, provides training in social and vocational skills in order to prepare clients for community living. This program, located on the Brainerd State Hospital campus, is operated in conjunction with the state Division of Vocational Rehabilitation. Four full-time Division of Vocational Rehabilitation Counselors are assigned to this program to work on the development of individual habilitation programs for each client. A work evaluation station in which the work abilities and needs of clients are assessed in a workshop-like setting, is housed in the CVRP building. Approximately 85% of the released target clients in 1972, 1973 and 1974 participated in the CVRP program.

Clients are chosen for participation in this program based on their vocational potential after a 2-week evaluation in the CVRP work station. They are further evaluated through psychometric testing and interviews by social service staff and the vocational rehabilitation counselors.

On a typical day in the CVRP program, clients awaken at 6:30, have breakfast and go on to their various placements at 8 a.m. Some clients work in institutional services, such as in the laundry or kitchen at Brainerd State Hospital. Others attend a vocational school in the community, or are in competitive employment jobs such as chambermaids in local hotels, dishwashers in restaurants, assistants in a barbershop, etc. All clients in CVRP are involved in some day placement activity for about 6 hours per day. Clients return to CVRP for supper and participate in evening activities such as physical education, dancing, movies, and swimming.

According to staff, all of the clients in this program received training in self-help, personal hygiene, housekeeping, meal preparation, behavior management, sex education, pre-academic skills, academic skills, use of community resources and public transportation, money management, preparation for job applications and interviews, and specific job skills. Individual habilitation plans covering these skills are developed by staff for each client. Appropriate goals are developed which are both measurable and time-limited. Specific staff members are then assigend to work on the individual training goals for each client.

The primary staff involved in this program for 1972, 1973, and 1974 were human services technicians, social workers, vocational rehabilitation counselors, nurses, and educators.

### 3.2.3. Program 6

Program 6 is a residential pre-release program at Brainerd for adult clients not yet ready to participate in CVRP. The activities at Program 6 are similar to those in CVRP, except that training in Program 6 is geared at a lower and more basic level to meet the particular needs of its clients. For example, there is more emphasis on self-help skills training and less on specific vocational skills in this program. Most clients in Program 6 attend day activity centers on the grounds of Brainerd State Hospital and/or are involved in various treatments such as physical, speech, and music therapy.

About 60% of the target clients released during the 1972-1974 period participated in Program 6. The primary staff involved in Program 6 are human services technicians, a unit director, social workers, psychologist, nurse, teacher, speech therapist, and a recreation therapist.

## 3.3 Sequence of Pre-Release Programs

Generally, when a client has progressed in Program 6, they move on to the more sophisticated CVRP program. Clients, however, are not required to go through Program 6 before advancing to CVRP. Most clients who function at a fairly high level are too advanced for Program 6--they are admitted directly to CVRP.

### 3.4 Overall Characteristics of Pre-Release Programs

Staff at Brainerd State Hospital perceive the following to be the major strengths of their pre-release programs:

- Working with the community--They view the programs as a resource to the community. In fact, they have provided so-called "outservice" (as opposed to "in-service") training to various staff and professionals in the community to help them prepare for residents who may be released into their communities. For example, they consult with local public schools about specific clients. In other cases, staff report that they have invited local professionals in the community to live at Brainerd State Hospital for a short period of time in order to orient them to the pre-release programs there.
- Policy of pre-placement visits--Brainerd State Hospital requires that clients visit their placement settings on a trial basis before they are actually released.
- Individualized programming--According to staff, all of the pre-release programs are based on the individual's strengths and work toward correcting her/his weaknesses.

The major weaknesses of the pre-release programs as perceived by the staff at Brainerd are:

- Lack of approariate resources in the community--The pre-release programs teach clients the skills necessary for community living but there are not placements currently available for these residents in the community. Staff feel that many resdients are adequately trained now, but "there's no place to go."
- Lack of staff and resources at Brainerd State Hospital--More staff and resources would result in better, more extensive pre-release programs.
- Federal licensing restrictions--Staff feel that some federal licensing requirements such as wage and work hour minimums prevent Brainerd from operating as comprehensive a pre-release system as they would like. If more funds were available, staff feel that more clients could get work experience for longer amounts of time.

Staff feel that they have overcome some of these weaknesses by reaching out to try and develop resources of their own. For example, they have involved large numbers of volunteers who help add dimensions to the programs not otherwise available. They also feel that the passage of the new Retardation Protection Act (see Section 1.2.1) will put pressure on the County Welfare agencies to develop community resources and service.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

The release procedures at Brainerd State Hospital begin when an interdisciplinary staff team determines, during a quarterly client review meeting, that a client is ready to be considered for community placement. The client's family and the county welfare agency in the community where the client may be placed are also involved in this determination. Once this decision is made, it is the responsibility of the county welfare agency to look for an appropriate community placement for the client. When a placement is found, the institution arranges for the client to visit the setting on a trial basis (ranging from 1 day to 2-3 weeks). If the trial visit is satisfactory, the county welfare agency finds a physician in the community who will serve the client should a medical problem arise. Final arrangements for the client's release are then made jointly by the county welfare agency and institutional staff.

According to staff at Brainerd State Hospital, the 3 most important criteria used to determine whether a client is ready to be placed in the community are:

1) functional level of client;
2) availability of residential placement in the community; and
3) availability of day program alternatives in the community.

No client is released until both a residential and day placement has been arranged. Of the clients released into the community since 1972, approximately 10% were initated primarily because of family initiative and 90% because of institution initiative.

### 4.2 Factors Affecting Release

Staff at Brainerd State Hospital characterize clients who are easiest to place in community settings as those who: have self-help skills; communicate well; are ambulatory; have no behavioral problems; and, whose financial problems have been resolved (i.e., there are adequate means of financial support for the client--family, job, or SSI). Conversely, clients with low self-help skills, who are non-ambulatory, or require a high degree of care (e.g., must be carried, toileted, fed, etc.) are most difficult to place in community settings.

While there is no "typical" community setting for clients with any given set of characteristics, clients who are perceived as "difficult to place" are more likely to be accepted into group homes or nursing homes than in natural, adoptive, or foster homes. However, even the group homes, according to staff, are often very selective in the kinds of clients they will accept. Some group homes screen out clients with ambulation problems, behavior problems, or low self-help skills.

### 4.3 Client Status Upon Release

In 1972 and 1973, Brainerd State Hospital employed two release categories:

1) "Discharged", in which the client is formally and indefinitely released from and off the rolls of the institution; and

2) "Trial Placement", in which the client is released from the institution on a trial basis for an extended period of time, yet remains on the rolls of the institution.

Of the clients released in 1972 and 1973, about half were discharged and half were placed on trial placement. In 1974, however, the trial placement status was discontinued at Brainerd State Hospital, so all clients released in that year and since that time have been discharged.

The trial placement status was discontinued because the institution felt that it no longer served its original purpose. Previously, people were placed on trial placement so that if they experienced a poor adjustment for any reason in the community, they could return to the institution without reapplying--that is, a bed was available for them. However, now that the institution population has been reduced so much, there is no longer a problem of a bed being available for the client who must return. Therefore, the trial placement status was considered unnecessary.

If a discharged client is having difficulty in her/his community placement and wants to return to Brainerd, staff at the institution and from the county welfare office first try to locate more appropriate services in the community for the client. If such services are not available, the discharged client can return to the institution. The institution, however, does not have the legal right to return the client to the facility involuntarily.

The fact alone that an individual resides at the institution has no effect on her/his legal powers to marry, to enter into employment contracts, to secure legal services, to leave the facility, or to refuse medical and other services offered by the facility.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

The follow-up of clients released from Brainerd State Hospital is the responsibility of the County Welfare agencies. Staff from Brainerd participate in the follow-up process only when the county request their services--usually for in-service training of community staff, counseling, short-term placements. According to staff at Brainerd, all clients released since 1972, regardless of their type of placement setting or release status, have been followed up by a County Welfare social worker at least once a month. Follow-up procedures used by these social workers include letters and telephone calls to clients as well as regular visits to their residential and day placement settings.

### 5.2 Support Services

#### 5.2.1. Agencies with Continuing Responsibility for Clients' Welfare

As discussed above, once a client is released from Brainerd, the County Welfare agency has primary continuing responsibility for ensuring the client's well-being--including the provision of continuing evaluation, follow-up services, and the securing of further changes in placement, if necessary. Brainerd State Hospital does not retain any continuing responsibility for the individual's well-being after the client has been placed.

#### 5.2.2. Types of Support Services Provided to Clients

The staff at Brainerd report that released clients receive social services monthly and medical services as needed directly from their County Welfare agency. The County Welfare agency contracts with other local service providers for educational, vocational and recreational programs for released clients. All clients, regardless of their placement setting or release status, have received these follow-up services. The follow-up services and programs were perceived by Brainerd staff to be adequate except for recreational programs. Staff feel that there are not enough leisure and recreational opportunities in communities for released clients.

### 5.3 Support Services Provided to Those Responsibile for Released Clients

Staff from Brainerd State Hospital will provide training to client's families when the County Welfare agency determines that such training is necessary. However, this determination is not made frequently. In those cases where training is requested, Brainerd staff generally offer counseling services and training in behavior modification methods to families in such areas as toileting and self-care. Group homes are offered similar training in addition to consultation on recreation and arts and crafts activities.

Similarly, Brainerd staff offer their services to teachers and employers of clients only when this is requested by the County Welfare agency. For example, Brainerd staff worked with a local school program on developing a team approach to conduct student assessments. The Division of Vocational Rehabilitation counselors have consulted with employers of released clients when this was requested.

## 5.4 Institution's Assessment of Released Clients' Adjustment to Community Living

Brainerd State Hospital conducts no formalized assessments of clients' adjustment to community living. However, the client's adjustment is ascertained informally through discussions with County Welfare social workers. Staff at Brainerd estimate a majority of the released clients are adjusting moderately well and many are adjusting extremely well.

The type of client making an excellent adjustment, according to staff, is a mildly or moderately retarded person who has a relatively high functional ability, is involved in a sheltered workshop or work activity center, and has evening activities available to her/him--in short, a person "accepted by the community." Staff stressed that recreational and leisure opportunities in the evening are essential for successful community adjustment. Many persons have a place to live and work, but no social and recreational outlets--this prevents them from actively becoming part of the community.

Clients making a moderate adjustment were described as usually severely or profoundly retarded, ambulatory, with some self-help skills. These persons usually live in group homes with supervision. A poorly adjusted client was characterized by staff as a "high functioning sociopath who feels the community owes him a living." This person is not well adjusted to accepting responsibilities which come with living in the community and may display behavior which runs contrary to the community's mores.

Brainerd staff cited 2 main reasons for the unsuccessful adjustment of some clients: 1) clients had behavior problems; 2) clients were non-ambulatory and/or required a high level of care and supervision. According to staff, more and more of the clients recently released or currently at the institution have psychiatric problems in addition to their mental retardation. This complicates their process of adjustment to community living and the process of the community accepting them.

## 6.0 RELEASED CLIENT PROFILE

As stated previously in Section 1.0 , released clients during the 1972-1974 period were grouped into two categories: "target" and "non-target" clients (see Glossary). Information will be presented first about the entire deinstitutionalized population of 1972-1974 and secondly, about the target and non-target clients. Since the focus of this study was on the released target population, more data was obtained for this group than on the non-target population.

Taking the released population as a whole, Brainerd State Hospital released a total of 397 mentally retarded people between 1972-1974. In 1972, 113 mentally retarded residents were released; in 1973, 155 residents were released; and, in 1974, another 129 clients were deinstitutionalized. The yearly releases represent 16% of the total institutional population for 1972, and 23% of the institutional population in both 1973 and 1974.

The level of retardation of the released residents was fairly evenly distributed during this period under study. 18% (or 72 clients) were classified as mildly retarded, 24% (or 94 clients) were considered moderately retarded, 27% (or 108 clients) were severely retarded, 24% (or 97 clients) were profoundly retarded, and 7% (or 26 clients) were not classified in one of these categories.

The age range of the total released population between 1972-1974 was predominantly aged 18 and older. Eighty-two percent of the released population was in this range. In 1972 and 1973, the slight majority of those released were female, while in 1974, roughly the same number of males and females were released.

The most common setting to which released clients were placed was to another institutional setting. Nearly half of the total released population (47%) were so placed. The next most common placement was to group homes, accounting for 29% of the total group. Natural/adoptive homes received 4% of the total group while foster homes and nursing homes each received 4%. Two percent of those released went to independently living settings.

The most frequent additional handicaps for the released population during this period under study were epilepsy, mobility limitations, and psychiatric problems.

## 6.1 Characteristics of Target and Non-Target Clients

Brainerd State Hospital released a total of 140 target clients between 1972 and 1974. Of these, 50 were released in 1972, 47 in 1973, and 43 were released in 1974. Non-target clients numbered 257 for the same three-year period. In 1972, 63 non-target clients were released, 108 were released in 1973, and 86 were released in 1974. Nearly a quarter of the target clients were aged 18 and under, while of the non-target clients, only 14% were children or youth. For both target and non-target groups, significantly more males were released in 1972 and 1973 than females, while in 1974, males and females were released in more equal proportions.

The level of retardation among target clients was fairly evenly distributed across all four categories: 33% were mildly retarded; 23% were moderately retarded; 28% severely retarded; and 16% profoundly retarded. Among the non-target released clients, a greater proportion of severely and profoundly retarded residents were released. For this group, 11% were mildly retarded, 27% moderately retarded, 30% severely retarded, and 32% profoundly retarded.

The most frequent handicapping condition in addition to mental retardation was psychiatric problems. Of the target and non-target clients, approximately 25% had psychiatric difficulties. Epilepsy, mobility problems, and deafness were also cited by staff as additional handicaps for both groups of released clients.

The overwhelming majority of both target and non-target clients were initially placed in Brainerd State Hospital by court commitment.

## 6.2 Skills of Target and Non-Target Clients Upon Release

According to staff, almost all of the target clients released between 1972-1974 possessed skills in the areas of self-help, personal hygiene, housekeeping, and behavior management. About half of these clients had skills in meal preparation, knowledge of birth control techniques, pre-academics, academics, community resources, public transportation, and money management. Approximately 40% of the target clients had received preparation in job applications and interviews and training in specific job skills.

Information on the specific skills training of non-target clients was not obtained. However, since many non-target clients participated in the same pre-release programs as the target clients, it may be assumed that non-target clients possessed many of the same skills as target clients.

### 6.3 Residential and Day Placements of Target and Non-Target Clients

As stated earlier, Brainerd State Hospital has a policy of having all residents visit the residential setting in which they might be placed prior to their actual release from the institution. Clients visit their prospective residential setting in the community at least once--some spend a weekend on a trial visit, others may visit for as long as two weeks.

Residential placements for the target group varied according to the age of the residents. Of the children and youth population (ages 6-18), the majority (71%) went to their natural or adoptive homes. About 8% were placed in foster homes and 21% went to group homes. Adults (ages 18-40) were most frequently placed in group homes (70%). Natural or adoptive homes received 22% of the adult target population, while 7% were placed in independently living situations. Foster homes accounted for only 3% of the adult target group's community placement.

Given that one of the criteria for inclusion in the target population for this study was that the community placement not be a nursing home or other facility which serves 100 or more clients, it was not unexpected that these two placements received a high proportion of the non-target population. A majority of the children and youth non-target population (54%) were placed in other institutions. Of the adults in the non-target group, 75% were placed in other institutions, 7% went to nursing homes. The next most common placement for adults was to group homes (15%) while for children and youth, natural and adoptive homes was the second most frequent community setting (24%). Foster homes received 16% of the children and youth age group; less than 2% of adults were so placed. Only one adult was placed in an independently living situation.

Brainerd State Hospital does not have the same policy of pre-release visits by clients to their future day placements as they do for client's residential placement. However, staff at Brainerd report that some clients did, in fact, visit their day setting before their release. The overwhelming majority of target clients went to sheltered workshops and/or day activity centers. Very few released residents were placed in competitive employment situations. Of the target clients, about 10% participated in public school programs upon release from the institution. Information on the types of day placements into which non-target released clients were placed was not obtained.

### 6.4 Readmissions

The number of target clients readmitted to the institution increased from 3 persons in 1972, to 5 persons in 1973, and 7 persons in 1974. About half of the persons readmitted were aged 6 through 18, and half aged 19 and over. Most of these persons had been in the community for 6 months to one year prior to being readmitted, although a few stayed as long as one to three years in their community settings before returning to Brainerd. Several persons had been living outside of the institution for as little as 6 months or less before they were returned to Brainerd.

For all three years, readmissions came most frequently from group home settings; other original placements for readmitted clients were natural, foster and nursing homes. In all but one case, readmitted clients had been discharged when released. The most commonly stated reason for readmission was "behavior problems." Staff at Brainerd also cited "family problems," "health problems," and revised planning and evaluations of released residents as reasons for readmissions.

Readmission rates and causes for non-target clients were not obtained.

## 7.0 PROFILE OF RELEASED STUDY GROUP

Of the 140 target clients released from Brainerd State Hospital between 1972 and 1974, 38 or 27% were interviewed during July and August of 1975 and are referred to as the study group (see Glossary). Of these study group members, two had returned to Brainerd by the time of the interviews and were interviewed there. In this section, information gathered from institutional staff, records, the study group members, his/her family, housemanager, social worker, or other contact persons in the community who was interviewed about the study group member will be presented. The information is not intended to serve as a validation of the information gathered from the institution about training, services, or follow-up provided to released clients, nor is it intended to be a "follow-up" of the released clients. Rather, it provides another view of the deinstitutionalization process. The descriptive information will be presented on the types of clients interviewed from Brainerd State Hospital as well as the study groups' perceptions of their problems since release. In addition, information will be presented from the families of the released clients on the institutional follow-up, the types of services received, and the types of problems encountered since release.

### 7.1 Study Group Characteristics

The age range of the study group was from 12 to 34 years, with an average age of 22 years. Over 80% of the group was white and 9% were black. Over one-third (38%) of the study group was mildly retarded, over one-third (35%) was moderately retarded, 21% were severely retarded, and 6% were profoundly retarded. The most common disabilities, other than retardation among the group were speech impediments (17%) and blindness (11%).

## 7.2 Residential and Day Placements

### 7.2.1 Residential Placements

About 60% of the study group members released between 1972 and 1974 were initially placed in group homes. At the time of the interview, only about one-third (36%) of the clients lived in such a setting. Almost one-quarter of the study group members initially were placed in a foster home; while almost half (47%) were currently living in that setting.

While 14% were initially placed in natural/adoptive homes, 11% were in such settings at the time of the interview. Another 6% were living independently.

### 7.2.2 Day Placements

Study group members released from Brainerd State Hospital were most frequently initially placed in competitive employment or sheltered workshops (69%) or in a school program (56%).* Two clients (6%) initially were not placed in any day program.

At the time of the interviews, however, over half (53%) of the study group members were in a competitive employment situation or a sheltered workshop. Almost three-quarters (72%) were involved in a school program, and 11% attended a day activity center. Approximately 6% of the study group had no day activity. Reasons cited most frequently by the family respondents for the absence of a day activity were that there were no appropriate programs or activities available in the community or that the client did not want to participate in a day program.

## 7.3 Follow-Up

Almost 90% of the respondents reported some follow-up contact by an institutional staff member since the client's release. The most frequently reported method of contact was by visit to the client's home. Other reported means of follow-up were through contact with a person responsible for the client's welfare (such as the social worker) or through telephone communication.

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*Percentages exceed 100% because of multiple day placements.

During the first six months after release, and during the most recent six months almost three-quarters (71%) of the study group members were reportedly followed up about once a week. The majority of the remaining clients were contacted on a monthly basis.

The vast majority (91%) of the respondents said they were satisfied with the follow-up received from trained staff. Only 9% said they were dissatisfied.

### 7.4 Case Managers

All of the respondents of the study group reported that there was a case manager or some person who was responsible for the client's well-being. During both the first six months after release and the most recent six months, almost three-quarters of the respondents (71% and 74% respectively) reported that this person was the houseparent who was in daily contact with the client during both time periods. For the other released study group members, contact with their case managers occurred most often monthly.

### 7.5 Services and Training

#### 7.5.1 Service and Training Need

The services cited most often as needed and not received by the released study group from Brainerd State Hospital were speech therapy (cited by over one-quarter of the respondents), social and/or psychological counseling, and occupational therapy.* The types of training cited as needed but not received by the study group were most frequently language skills (cited by one-quarter of the respondents), dealing with emergencies, and travel skills (getting around the neighborhood).

The support services most frequently mentioned by the respondents which they felt they needed yet did not receive were support and/or training prior to the client's coming to the residence (cited by one-quarter of the respondents), on-going family counseling, and consultation for handling specific problems.

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*See Glossary for a list of the services and training on which information was collected.

### 7.5.2 Service and Training Use

The study group reportedly used an average of four services since their release, while they reportedly received training in an average of 12 skill areas.

Of the services used by the clients, respondents reported that almost half (47%) of the services were provided by the institution, while almost a third (31%) of the services were provided by community agencies. Community residences provided 11% of the services, and the clients' day programs provided 9%. Other community sources provided 2% of the services used.

Nearly three-fourths (70%) of the training received by the study group was provided by the community residences, while nearly a quarter (22%) was provided by the clients' day programs. Community agencies provided 5% of the training, while the institution provided 3%.

## 7.6 Problems

Family respondents reported that family relationships, behavior problems, and social relationships were the most serious problems encountered by the study group members since release.

Study group members were asked which problems they considered to be the most difficult since leaving the institutions. The majority of clients responded that they were lonely. Other difficulties mentioned were handling family relationships, budgeting money, and psychological problems.

There were two study group members who returned to the institution and were living there at the time of the interviews. Family respondents cited the reasons these clients returned to the institution were that the family readmitted the client and/or behavior problems developed.

## 7.7 Adjustment

Over three-quarters (76%) of the study group members were perceived by the interviewer to have social relationships in the community. One-quarter (24%) of the clients seemed socially isolated.

The interview described the majority (83%) of the study group members as satisfied with their current life. Approximately 6% of the clients appeared somewhat dissatisfied while about 16% of the clients were not rated by the interviewers.

Almost three-quarters (71%) of the study group members appeared to have adjusted well to living in the community. Approximately 15% were perceived to be poorly adjusted while the interviewers were unable to describe the adjustment of the remaining 15% of the clients.

## CHAPTER 6.0: DOVER STATE SCHOOL

### 1.0 INTRODUCTION

### 1.1 Overview

The Dover State School* is a public residential facility for the mentally retarded located in a midwestern state. Under the auspices of the State Department of Mental Health, it serves mentally retarded people of all levels of retardation. Dover's overall population has decreased in recent years from approximately 1,300 residents in 1972, to 1,062 residents in 1974, and by 1975, figures showed an enrollment of 912 clients. Thus, between 1972 and 1975, there has been a 30% reduction in the institutional population. During this period, females have comprised less than 40% of the entire population. Over 80% of the residents were over age 19.

While Dover staff were unable to provide information on the distribution of its residents according to levels of retardation for the entire 1972-1974 period under study, figures were available for 1974 and 1975. In 1974, approximately 13% of the population was considered either borderline or mildly retarded. Moderately retarded clients constituted 16% of the population, severely retarded were 43% of the enrollment, and profoundly retarded clients were 29% of the population. 1975 figures show a similar distribution with the exception of a slight reduction (to 8%) in the borderline and mildly retarded group, and a slight increase (to 33%) of profoundly retarded residents.

The incidence of other handicapping conditions besides mental retardation among Dover residents was also available for only 1974 and 1975. The proportions of residents with specific conditions did not change for these two years. The most common additional handicap was cerebral palsy, affecting nearly 45% of the enrollment for both years. Nearly a third of the enrollment was epileptic for both years.

Total operating costs at the Dover State School have steadily increased in recent years. In 1972, expenditure levels were put at $11,135,000 and increased by 12% in 1973 to $12,481,000. By 1975, total expenditures were a reported $14,196,000.

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*Dover State School is a fictionalized name for this facility.

The number and types of staff employed at the Dover State School were available only for 1975. There were a total of approximately 1,100 employees, 43% of whom were attendants in the facility. Nurses were the next largest staff group, comprising 4% of the total staff.

## 1.2 State Context

### 1.2.1 State's and Institution's Deinstitutionalization Policies

The state has developed policies and legislation which set forth specific goals relating to the deinstitutionalization of mentally retarded people. One statute, passed in 1973, mandates that each county or cluster of counties must provide the 16 program components required under the federal Developmental Disabilities Act. This ensures that clients moving out of an institution will have access to an appropriate spectrum of services within their local communities.

Pursuant to the federal Title 19 regulations of the Social Security Act (Medicaid), the State has mandated that all clients who are determined to be capable of other than institutional living under the Title 19 evaluation, be placed in community settings within a one-hour drive from their families' homes.

## 1.3 State Legislation Relating to Deinstitutionalization

### 1.3.1 The Right to Education Law and Its Impacts

The State's education law, which covers all handicapping conditions, at all levels of severity, was passed in 1973. The law states that any handicapped individual, aged 3-21 years, is entitled to those services available to her/his chronological peers, insofar as is possible. If a special education program is necessary, the law requires that the program be outlined by a multi-disciplinary team which includes the person's parents. An appeal procedure is also specified in the event that parents disapprove of the program. This law is expected to be fully implemented by the fall of 1976, and had been partially implemented by the spring of 1975.

As perceived by staff at Dover, the Right to Education Law has had the following impacts:

- Significant increase in the number of clients served by educational and pre-release programs at the institution;
- Very significant increase in the number of clients released from the institution into community settings;
- Decrease in the readmission rate of released clients;
- Increase in the number of clients placed in family or foster homes; and,
- Very significant increase in the number of clients placed in group homes in the community.

### 1.3.2 The Periodic Review Law and Its Impacts

While the state has not enacted periodic review legislation, the Dover State School has an administrative policy mandating periodic assessment of clients. To comply with licensing requirements as an Intermediate Care Facility under Title 19 of the Social Security Act, the State School's policy states that each client must receive an annual medical review, social service plan, and inter-disciplinary team review. This policy was established in the spring of 1974. During that year, the process was brought to partial implementation, with between 11% and 85% of the institution's clients being reviewed.

Staff at Dover felt that the institution's periodic review policy has had the following impacts:

- Small increase in the number of clients served by educational and pre-release programs at the institution;
- Very small increase in the number of clients placed in family or foster homes; and,
- Small increase in the number of clients placed in group homes in the community.

The relatively small extent of the impacts noted above is due in part to the fact that the policy was enacted in 1974, and had therefore, affected only a limited number of released clients as of the spring of 1975.

### 1.4 State Litigation Relating to Deinstitutionalization and Its Impacts

During 1972, the state was involved in a suit relating to the institutionalization of the mentally ill. The Department of Mental Health, however, elected to apply the tenets of the suit to persons with developmental disabilities as well. The decision, which was given in 1973, requires that due process be ensured to institutionalized persons. According to this decision, before being committed to an institution, persons must be represented by an attorney not serving any other purpose in the court (this decision is now in side appeal for clarification.) One of the results of the suit was the enactment of the State Social and Legal Services Act, which allows for several different levels of guardianship.

According to staff perceptions, the suit has had the following impacts on the Dover State School:

- Increase in the number of clients released from the institution into community settings;
- Decrease in readmission rate of released clients;
- Significant increase in the number of clients placed in family or foster homes;
- Significant increase in the number of clients placed in group homes in the community;
- Small increase in the number of clients placed in semi-independent living situations; and
- Increased impetus toward protection of client rights.

## 2.0 CLIENT ASSESSMENT PROCEDURES

According to Dover staff, clients released in all three years under study received multi-disciplinary reviews. These consisted of an independent medical review and a social work review. The clients' social workers then coordinated the compilation of other assessments as appropriate from program staff involved with the clients. Dover staff report that these assessments always included educational, nursing, and cottage life components.

Across all three years, medical and educational assessments were provided to all clients on an annual basis, and psychological assessments were provided as needed. In 1974, annual social and vocational assessments were added to the process. Staff involved in the assessment procedure included the following: superintendent, physicians, social workers, nurses, vocational rehabilitation counselors, direct care staff, and educators. In addition, speech and physical therapists were included *if* they were involved in a client's treatment program.

Dover staff report that all clients released during the three-year period reviewed or discussed their assessment results with staff. During the latter part of 1973 and during 1974, clients actually participated in their own assessments, and their opinions were given consideration in the assessment results. Families, guardians, and advocates of clients were not usually invited to participate on regular assessments of clients. However, during 1974, potential houseparents, community board members, community program staff, and vocational staff were invited to participate in the regular assessments of released clients as appropriate.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction

The Dover State School has three residential pre-release programs which serve both children and adults. Target clients released from 1972-1974 may have participated in any one of these separate pre-release programs which are designed to prepare them for community living. In addition, a sheltered workshop on the institution grounds was available to prepare clients for jobs in the community though no released target clients participated in this program during the period under study. The three residential pre-release programs are described in the following sub-section. It should be noted that there is no specified sequence for participation in the pre-release programs.

### 3.2 Program Description

#### 3.2.1 Program A

Program A, a separate residential pre-release program with a maximum capacity of 48 clients is intended to change problem behaviors of clients, thus enabling them to return to community living. Individual treatment programs are set up for each client. Community involvement and activities are encouraged as a means toward normalization and eventual transition of the client to the resident's home community. Clients are chosen for participation in Program A on the basis of referrals from the community or from within the institution. Most clients are referred to Program A because of behavior management problems. Approximately half of the 27 target clients released in 1972* had participated in Program A; this number declined in following years, so that in 1974, less than 20% of the 63 released target clients had participated in the program.

A typical day in Program A begins at 6:30 a.m. Before breakfast, clients do chores and receive payment in tokens, depending on the quality of their work. They pay for breakfast, then proceed to their individually scheduled activities, such as school, work, or therapy. During these activities, they are evaluated and paid according to their performance. At the end of the day's activities, clients may go to the "token hut" to spend token they have earned. Evening is a time for free activity for clients.

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*See Section 6.0 for a description of 1972-1974 released clients.

Staff report that clients released from Program A during the three-year period all had self-help, personal hygiene, and housekeeping skills and had no major behavior problems. None of the clients released in 1972 and 1973 had been trained in the use of community resources, but over half of those released in 1974 had skills in this area. From 20%-30% of the clients released in 1972 had been trained in pre-academic and academic areas, but this number declined considerably for those released in the following two years. Some of the clients released in 1974 had also received training in meal preparation, sex education, and use of public transportation.

Much of the training in Program A is provided to clients on an individual basis or in small groups by various staff at the institution. Use of community resources is taught through field trips to banks, stores and community recreational facilities, with clients and staff using public transportation. Behavior modification techniques are used to eliminate clients' inappropriate behaviors. Clients may earn special privileges on the basis of appropriate behavior, and may lose privileges when inappropriate behaviors occur.

Staff reportedly spending the greatest amount of time involved in Program A include teachers, speech therapists, direct care staff, and nurses. Social workers, psychologists, psychiatrists, and the unit director are also heavily involved. Other staff working with clients in this program include occupational and physical therapists, volunteers, and the Superintendent of the Dover State School.

### 3.2.2 Program B

Program B is another separate residential pre-release program which prepares clients as much as possible to enter into community life. Clients' individual needs are identified, and deficiencies are corrected, before they are released into the community. Clients are usually expected to be released into the community within two to six months after beginning participation in Program B. None of the target clients released in 1972 or 1973 had participated in Program B; approximately 80% of those released in 1974 had participated in the program.

On a typical day in Program B, clients awaken and perform personal hygiene tasks before breakfast. After eating, they go to individually scheduled activities such as work or day care. Most clients work for three hours per day, although some work as long as six hours; many work half of the day, and attend school during the other half. Lunch is served family-style at the unit. After work and/or school, clients devote the late afternoon and evening to recreational activities; thay may shop or use the unit's recreation rooms, which feature pool and ping-pong tables and stereos.

According to staff, all of the clients in this program received training in self-help skills, personal hygiene, housekeeping, and money management, and the majority had been trained in the use of community resources. Half had also received training in meal preparation, and smaller numbers received some training in use of public transportation, and behavior management.

Training in Program B is usually performed on a one-to-one or small group basis by various appropriate staff. Clients are encouraged to take a good deal of responsibility for their activities as part of the training. For example, they have their own money, and are encouraged to open bank accounts in order to insure their money management skills.

Direct care staff, nurses, and physicians are the staff types most involved in Program B. Input to clients is also provided by activity and occupational therapists, social workers, psychologists, and the unit director. Other staff peripherally involved in the program include psychiatrists, teachers, speech and physical therapists, volunteers and the Superintendent of the State School.

### 3.2.3 Program C

Program C, which operated during 1972 and 1973, trained clients in specific job skills, then placed them in employment situations in the community. Clients were chosen for participation in Program C on the basis of inter-disciplinary staff recommendations. Individuals were rated on social competence, vocational aptitude, and emotional stability; those scoring the highest were accepted into the program. All clients in

Program C had IQ scores of over 50, and were between the ages of 16 and 45. Of those target clients released in 1972 and 1973, approximately one-third had participated in Program C.

Clients in Program C were usually awakened at 6:00 a.m. After breakfast, they cleaned their living area and then reported for work or school. They returned to the living unit for noon lunch with staff, and then went back to work or school until 4:00 p.m. Evening activities included field trips, chores (e.g., laundry), special academic tutoring, and the use of the unit social room for ping-pong and pool.

During the two-year period, all of the clients in Program C received training in the following areas: self-help skills, housekeeping skills, meal preparation, behavior control, use of community resources, money management, preparation for job applications/interviews, and specific job skills. A limited number of clients in both years received pre-academic and academic training. Training activities and methods used in Program C were much the same as those used in Program B.

Vocational rehabilitation staff, direct care workers, and teachers were most involved in Program C. Volunteers, psychiatrists, psychologists, physicians, and nurses also had a good deal of input into the program. Other staff with occasional involvement were speech, occupational, and physical therapists, and the Superintendent of the State School.

## 3.3 Overall Characteristics of Pre-Release Programs

Three major strengths of Dover's pre-release programs were stressed by institution staff. First, staff feel the pre-release programs effectively prepare clients for community living. The programs are supported by the administration and can, therefore, acquire needed staff and facilities within the institution. Moreover, there has been effective inter-disciplinary involvement since 1974, leading to the development of more appropriate release plans for clients.

Several major weaknesses in the pre-release programs were also noted. Sex education in the programs is inadequate. Staff members also feel that pre-release programs at the State School should include more community involvement for clients prior to their release, such as more frequent pre-placement visits, and more community experiences. Finally, pre-release programs should be given greater publicity in the surrounding communities. At present, staff feel the institution's public education program is lacking both in quality and quantity.

Efforts are being made to overcome these weaknesses. In the area of sex education, several individual staff members have set up informal discussion groups for clients on the subject of hygiene. The State School has also attempted to create more community experience for clients. Community members have been invited to the institution to visit programs there, and staff have been encouraged to escort more clients to community facilities. In relation to public education, the State School has started a quarterly newspaper telling of news in the institution. This is circulated to families of clients and community leaders. The State School has also obtained films for staff to use in making speeches to community interest groups. Finally, a Normalization Committee has been established which includes community members; the committee has led workshops for institution staff in the area of client rights.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

Clients are referred to the Placement Committee at Dover State School after a review has been made in an inter-disciplinary staff meeting which is held to assess the client's readiness for community placement and the type of residential placement most appropriate. Clients are generally referred for placement by the School staff or by their families; most often, they are referred by School social workers. The inter-disciplinary staff involves the client's social worker, physician, direct care staff, and all program staff involved with the client. Recommendations are developed by this group who then forward their recommendations to the Placement Committee. The Placement Committee, in turn, reviews the plans formulated by the inter-disciplinary team and determines whether or not they meet the client's specific residential and program needs. The three most important criteria used to determine the client's readiness for community placement are: (1) his/her functional level; (2) availability of residential placement in the community; and (3) availability of day programs in the community in which the resident will be placed.

### 4.2 Factors Affecting Release

Clients whose appearance is fairly normal, and who have little family involvement, are considered easiest to place by Dover staff. These clients typically have no or few emotional problems, and possess all necessary self-help skills. Most of the clients who are considered easy to place have "institutional personalities;" that is, their behaviors are fairly predictable, and they are compliant. They will either make it on their own completely, or they will be very dependent on the people who care for them.

Clients who are difficult to place are those with few or no self-help skills, and those with behavior problems. Multiply handicapped individuals, or those who have noticeable physical handicaps or impairments are also considered to be difficult to place. In some cases, clients who are motivated to be independent are also difficult to place, since they tend to fare poorly in group-oriented settings.

Typically, clients placed in their natural homes are children who have reached their treatment goals. Such placements are also dependent on the existence of an educational program in the community. Clients who are still learning self-help skills, who need one-to-one attention, but who have few behavior problems, are more often placed in foster homes. Foster homes accept multiply-handicapped individuals than other types of placements. The capable client, one who has mastered self-help skills and needs to develop good peer relationships, is usually placed in a group home.

### 4.3 Client Status Upon Release

Across all three years, the large majority of client releases were institution-initiated. In all cases but one (which occurred in 1974), clients were released on extended visit status, as opposed to discharge status.

Several legal powers are limited by the fact that a client is residing at the Dover State School. These include the client's right to marry, enter into employment contracts, leave the facility, and refuse medical or other services offered by the institution. Clients who are released on extended visit status retain limited powers in the areas of marriage and the ability to refuse services offered by the facility. The legal powers of clients who have been discharged are not limited in any way. The circumstances of original placement at the institution do not have any effect on clients' deinstitutionalization options.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

The institution provides follow-up for clients released on extended visit status. According to staff, all clients placed in foster care homes are visited by institution staff at least once a month. All clients in vocational placements and in room-and-board (semi-independent) settings are visited by staff at least once every three months. In addition to these visits to clients' home and work settings, letters and phone calls are also used to follow-up client progress. Where appropriate, follow-up services are provided by County Developmental Disability Boards, County Departments of Social Service, and the State Department of Corrections.

### 5.2 Support Services Provided to Clients

#### 5.2.1 Agencies with Continuing Responsibility for Clients' Welfare

Clients on extended visit status remain the primary responsibility of the institution which provides continuing evaluation and follow-up services and secures changes in placement, if necessary. The County Developmental Disability Boards have primary continuing responsibility for clients released on discharge status. These boards, being decentralized and located in areas in which released clients reside, may provide services directly or purchase them for clients.

During the period under study, clients had the right to return to the institution voluntarily, without regard to waiting lists or waiting periods. If the client was originally committed to Dover State School voluntarily (e.g., self-admission or admission by consent of a parent or guardian), the State School does not have the right to return her/him involuntarily after release. The State School does possess this power in the case of clients committed through court action.

#### 5.2.2 Types of Support Services Provided to Clients

Across all three years, various follow-up support services were provided to released clients, regardless of release status or type of community placement. Staff report that all clients received social services, medical care, and educational or vocational training, and 75%

received follow-up support services with regard to recreation. Medical care was provided on an as-needed basis. Educational and vocational programs occurred daily. The frequency of support services in the area of recreational programming varied according to the community in which the client was living. During 1972 and 1973, social services were provided to released clients on a quarterly basis. In 1974, these services were provided monthly.

Across all three years, social services were provided by the Dover State School. The State School also provided medical care in 1972 and 1973, but in 1974 this service was delivered by private vendors within local communities in which clients resided. Educational, vocational, and recreational programs were provided by various community agencies, including schools, local Associations for Retarded Citizens and state programs.

During 1972 and 1973, the institution staff most often involved in providing support services to released clients were social workers, physicians, psychologists, vocational rehabilitation counselors, and educators. In 1974, staff most often involved included social workers, psychologists , vocational rehabilitation counselors, educators, and the Superintendent of the institution. Institution staff viewed all support services as being adequately provided, with the exception of those related to recreational programming. This service was perceived to be inadequate during the three-year period.

### 5.3 Support Services Provided to Those Responsible for Released Clients

During 1974, the Dover State School did provide some support services to the families of released clients. Natural families were invited to attend inter-disciplinary staff meetings on clients, as were foster families and group home houseparents when appropriate. The State School did not provide support services to the teachers or employers of released clients during 1972-1974.

### 5.4 Institution's Assessment of Released Clients' Adjustment to Community Living

In order to assess clients' adjustment to community living, social workers record each follow-up contact made with clients. These staff members particularly note their estimation of the client's adjustment to her/his new living situation. Dover staff list the following criteria as used by staff to assess clients' adjustment: (1) program and facility appropriateness; (2) clients' opinions of their adjustment; (3) input from agencies and individuals providing services to the client; and (4) input from the client's social worker.

According to institution staff, of those target clients released during the three-year period, about 20% are adjusting extremely well, about 50% are adjusting very well, 20% moderately well, and 10% either fairly well or poorly. Clients making an excellent adjustment to community living typically have good self-care skills, and have no or few behavior problems. Staff also emphasize that the type of setting is an integral part of a client's adjustment process and that clients without developed skills may still make an excellent adjustment to community life if the setting is supportive.

Clients making moderate adjustments to community living may have periodic outbursts which must be understood and dealt with appropriately by those responsible for the client. Most of these clients are living in semi-independent or independent settings.

Clients adjusting poorly to community living have usually been mistakenly placed in settings which are inappropriate to their functioning level. In such cases, behavior problems or regression in skills may occur. The philosophy of the State School holds that the individual cannot be assessed in isolation from his/her environment. Thus, most poor adjustments are seen as being due to inappropriate placements or lack of adequate support services for the client. For example, the client's "family" may not know how to deal with his/her problems, and/or may not want to face them. The individual's functioning level may not be understood or accepted.

## 6.0 RELEASED CLIENT PROFILE

As stated in Section 1.0, released clients were grouped into two categories: target and non-target clients (see Glossary for definitions). Since the focus of this study is on the target group, more information was gathered for this population than on the non-target clients. In the following discussion, information will first be presented on the released clients as a whole, and secondly, on the target and non-target groups separately.

Dover State School released a total of 432 clients between 1972 and 1974. In 1972, 108 clients were released, representing 8% of the total institutional population for that year. In 1973 and 1974, 162 clients were released each year, representing 13% of the institutional population in 1973, and 15% in 1974. During the first two years under study, males were in the slight majority of released clients, while in 1974, nearly three-quarters of the released clients were female. Of the released group, 20% were under age 19.

The released clients from Dover State School were fairly evenly distributed according to level of retardation. About 14% of those released were considered borderline mentally retarded, Nearly a quarter were mildly retarded and nearly a quarter were moderately retarded. Severely retarded clients comprised about 28% of the released group, while profoundly retarded clients made up 9% of those released.

The most common setting to which one-third of Dover's released group (both target and non-target) were placed was to nursing homes. Group homes received a little over a quarter (27%) of the released clients while 11% were placed in independent living situations. About 7% went to natural/adoptive homes and 6% to foster homes. Finally, about 15% were placed in other types of unspecified settings and 2% were placed in semi-independent living situations.

### 6.1 Characteristics of Target and Non-Target Clients

Of the total number of clients released from Dover State School between 1972 and 1974, 34% or 140 were considered target clients for this study. Twenty-seven target clients were released in 1972 (2% of the institutional population), 50 target clients were released in 1973 (4% of the institutional population), and another 63% target clients were placed in community settings in 1974 (6% of the institutional population). Males were in the slight majority during all three years of the study. Almost 70% of those released were between the ages of 18 and 40 years.

Of the target clients, almost three-quarters were either mildly or moderately retarded. Twenty-seven percent were severely retarded, and only one percent was profoundly retarded.

Across all three years, three-fourths of the released target clients had originally been committed to the State School by the courts, and one-fourth by authorization of a parent or guardian.

Non-target clients released from Dover State School differed from the target clients in terms of numbers released and levels of retardation. A total of 292 non-target clients were released during the three year period under study. In 1972, 81 non-target clients were released (6% of the institutional population of that year), in 1973, another 112 non-target clients were placed out of the institution (9% of the institutional population), and in 1974, 99 clients were released from the State School (9% of the institutional population). Females were in the minority for both 1972 and 1973, while in 1974, all the released non-target clients were female. Nearly 85% of those released were over the age of 18.

A little more than half of the non-target clients were either borderline mildly, or moderately retarded. Twenty-eight percent were severely retarded and 12% were profoundly retarded.

## 6.2 Skills of Target and Non-Target Clients Upon Release

Staff report that all of the clients released during 1972-1974 had self-help skills, and most possessed pre-academic skills, personal hygiene skills, and housekeeping skills, although the percentage of clients with pre-academic skills declined somewhat in 1974. More than half of those released had no or few behavior problems. In 1972 and 1973, approximately half of the released clients also had academic and money management skills were able to use community resources, and could prepare for job applications and interviews. However, the percentage of clients with those skills declined somewhat in 1974. Over the three-year period, very few of the released clients had meal preparation skills or had formal training in the area of human sexuality.

## 6.3 Residential and Day Placement of Released Target and Non-Target Clients

Over half the target clients were placed in group homes. The next most frequent community placement was independent living situations where almost 20% of the target clients were placed. Fifteen percent were placed in natural homes, 6% in foster homes, and 4% in semi-independent cooperative apartment settings.

For the non-target clients, nearly haf were placed in nursing homes. Another 17% were placed in other institutions. Fourteen percent were released to group homes, 8% to independent living settings, 6% to foster homes, and 4% to natural homes. About 3% were placed in semi-independent settings.

During 1972 and 1973, about 10% of the target clients had visited their residential placements prior to release. This percentage doubled in 1974.

In 1972 and 1973, about a third of the target clients were placed in competitive employment positions. The next most common placement was to public school program. Relatively small percentages of clients released during these two years also went to workshop placements and day activity centers. The most common placements in 1974 were to day activity centers, workshops, and public school programs, with an almost equal percentage of released clients going to each type of placement; virtually none of the target clients released in 1974 went into competitive employment. During 1972 and 1973, 5% of the target clients visited the day settings in which they would be placed. This percentage doubled in 1974.

Information on the day placements of non-target clients was not obtained.

## 6.4 Readmissions

Approximately 3% of the 77 target clients released in 1972 and 1973 were subsequently readmitted to the institution, and 7% of the 63 target clients released in 1974 were readmitted. All of the clients readmitted from 1972 releases were adults, as were two-thirds of clients from 1973. However, slightly over half of those readmitted after release in 1974 were children. Two-thirds of the clients readmitted after release in 1972, and all of those readmitted after release in 1973, were female. However, slightly over half of those readmitted after release in 1974 were male.

Of those clients released in 1972, readmissions were equally divided among persons who had been in the community for less than six months, those who had been in the community for six months to one year, and those who had been there for one to three years. The majority of clients released in 1973 and 1974 and subsequently readmitted had been in the community for six months or less.

Readmissions of target clients released in 1972 were equally divided among those who had been placed in natural homes, foster homes, and semi-independent living situations. The majority of those readmitted from 1973 releases had been living in semi-independent situations, and the majority of those readmitted from 1974 releases had been living in group homes. All clients readmitted to the Dover State School during the three-year period had been released on extended visit status.

The most common reason for readmission of target clients across all three years was behavior problems. Other factors leading to readmission included inability to adjust to the new living situation, medical problems, alcoholism, and consistent running away from the community placement.

## 7.0 PROFILE OF STUDY GROUP CLIENTS

Of the 140 target clients released from Dover State School between 1972 and 1974, 36 or 26% were interviewed during July and August of 1975 and are referred to as the study group (see Glossary). In addition, five study group members had subsequently returned to Dover State School after their release and were interviewed at the institution. In this section, information will be presented on the study group which was collected from institutional staff, records, the client study group, and his/her family, social worker, housemanager, or other contact person interviewed about the client. The information presented is not intended to serve as a validation of the information collected from Dover State School not as a "follow-up" on the study group clients. Rather, the intent is to give a generalized overview on the types of clients released from Polk who were interviewed along with descriptive information on the services and training received since release, the types of problems encountered as perceived both by the client and his/her contact person.

### 7.1 Study Group Characteristics

There was a range in ages of the study group from 9 to 38 years, with an average age of 24 years. The vast majority of the study group (97%) was white. Three percent of the study group was black. Over one-third of the study group (37%) was mildly retarded, 30% were moderately retarded, over one-quarter (27%) was severely retarded, and 3% were profoundly retarded. The most common additional disability other than retardation reported among the group were speech impediments (36%), psychological problems (16%), and blindness (10%).

### 7.2 Residential and Day Placements

#### 7.2.1 Residential Placements

About two-thirds (65%) of the study group clients released between 1972 and 1974 were initially placed in group homes and at the time of the interview a similar percentage (64%) was living in such settings. Almost one-fifth (19%) of the study group was initially placed in a semi-independent living situation, although at the time of the interview only 10% were living in such a setting. Foster home placements did not vary significantly with 7% initially placed in foster homes and 10% residing in such settings when interviewed. Similarly, while 10% of the study group was initially placed in their natural/adoptive homes, 13% of the study group were in this type of setting when interviewed.

### 7.2.2 Day Placements

The most frequent initial placement of the study group members released from Dover State School was in a competitive employment or sheltered workshop situation (14 or 45% of the group) or in a school program (45%).* About a third of the group were initially placed in a day activity center. Two clients (7%) were not initially placed in any day program.

At the time of the interviews, however, about two-thirds (65%) of the study group members were in a competitive employment or sheltered workshop situation. Almost half were involved in a school program (45%) while another third attended a day activity center. About 7% of the study group had no day activity. Reasons cited most often by respondents for the absence of a day activity were that there were no appropriate programs or jobs available in the community or that the client was reluctant to participate in a day activity. Some respondents also cited the client's exclusion from an activity because she/he could not meet the requirements or demands of the program.

## 7.3 Follow-Up and Study Group Clients

Family respondents of the study group were asked if there had been an institutional follow-up contact since the client's release. Over half of the respondents (58%) reported some follow-up by an individual staff member. The most frequently reported method of contact was by visiting the client's residence. Other reported means of follow-up were contact with someone responsible for the client's welfare or by visit to the client's day placement.

The amount and frequency of follow-up contact tended to decrease over time. During the first six months after the client's release, half (50%) of the study group were reportedly followed-up on a monthly basis. However, during the six month period prior to the interview, a little more than a quarter (29%) had institutional follow-up on a yearly basis and 6% of the family respondents reported no institutional follow-up.

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*Because of the possibility of multiple day placements, percentages exceed 100%.

Family respondents were asked how satisfied they were with the follow-up provided. The vast majority (94%) were satisfied with the follow-up they received while 6% said they were dissatisfied.

## 7.4 Case Managers

Most of the respondents of the study group (90%) reported that there was a case manager or some person who was responsible for the client's well-being. Almost three-quarters of the case managers during the first six months after release and during the most recent six months were parents or housemanagers. Approximately one-quarter (26%) were counselors from the community. According to over three-quarters of the respondents, study group members were in daily contact with case managers for both time periods.

## 7.5 Services and Training

### 7.5.1 Services and Training Needs and Use

Family respondents were asked about the success and training needs of the released study group.* The services cited most often as needed but not received were dental services and speech theraphy. The types of training cited as needed but not received by the study group were language skills, reading and writing, and dealing with emergencies.

The support services most frequently mentioned by the family respondents which they felt they needed but did not receive were parent or professional associations (cited in over one-quarter of the cases) and on-going family counseling.

Family respondents were asked about the clients use of support services and training in various skill areas. The study group reportedly used an average of six services since their release, while they reportedly received training in an average of 15 skill areas.

### 7.5.2 Services and Training Providers

Family respondents were also asked about the providers of services and training received by Dover State's released study group. Of the services used by the clients, almost half (43%) were received from a community agency, while over a quarter (26%) were received from the clients' day programs. The community residences reportedly provided 20% of the services, while 11% of the services were provided by other community sources. Dover State School provided none of the support services to the study group.

Of the training received by the released study group, over half (58%) was provided by the community residence, while over a third (37%) was provided by the clients' day programs. Community agencies provided 5% of the training, while the school provided no training to clients after their release. Other community sources provided less than 1% of the training received by the study group.

## 7.6 Problems

Family respondents were asked a series of questions regarding the types and degree of severity of problems which study group members may have experienced since their release from the institution. Respondents reported that keeping a job was the most serious problem encountered by the study group members. Other problems mentioned by respondents included managing money, family relationships, loneliness, medical problems, and behavior problems.

Study group members were asked about the problems they had experienced since leaving Dover State School. Over one-third of the released study group mentioned loneliness as being a problem. Other mentioned areas of difficulty were handling family and social relationships and budgeting money.

Reasons for returning to the institution given by family respondents of returnees were that the family readmitted the study group member or that the study group member had behavior or psychological problems.

## 7.7 Adjustment

Following the interview session, interviewers were asked to record their perceptions about the study group member's adjustment to the community along three dimensions: degree of social isolation, degree of client satisfaction or happiness with life in the community, and overall adjustment to the community.

Over three-quarters (77%) of the study group members were perceived by the interviewers to have some or many social relationships with other persons while 20% of the clients appeared to be isolated from social relationships. The interviewers were unable to judge the social isolation of approximately 3% of the clients.

Almost two-thirds (60%) of the study group members appeared at least somewhat satisfied with their current life. Approximately 13% of the clients appeared somewhat dissatisfied and 10% seemed to be very dissatisfied with their life in the community. The interviewers were unable to judge the client's satisfaction in 17% of the cases.

The majority of study group members (83%) appeared to be well adjusted to living in the community. Only 7% were perceived to be poorly adjusted. The interviewers were unable to determine the adjustment of 10% of the clients.

# CHAPTER 7.0: HUDSON STATE SCHOOL

## 1.0 INTRODUCTION

### 1.1 Overview

Hudson State School* is the only state-supported residential school for the mentally retarded in a rural New England state. When it was first established in 1915, its 450-acre site accomodated 42 clients. Hudson's population peaked in 1968 when 668 clients were enrolled at the facility. Since the late 1960's, more alternative placements have become viable through the establishment of local community mental health centers. As the different communities in the state became more capable of providing support to released clients, Hudson developed a formalized program of pre-release training and services.

Hudson's population has been gradually decreasing in numbers. During the period under study (1972-1974), Hudson's enrollment decreased by 15%, from 521 residents in 1972 to 444 residents in 1974. Its 1975 enrollment was 450 clients. In addition, some basic changes in the demographic characteristics of its residents have been noted in recent years. For example, in 1972, 39% of the population residing at Hudson was female, and nearly half the population was under age 18. In 1974 and 1975, by comparison, 43% of the population was female, and the children and youth population accounted for only 35% of the enrollment.

Changes in the distribution of residents according to levels of retardation have been slight. In 1972, clients at Hudson were fairly evenly spread across all four categories: 14% mildly retarded, 31% moderately retarded, 31% severely retarded, and 24% profoundly retarded. In 1974 these proportions were substantially the same. The 1975 residential population of 450 clients was reported to be 13% mildly retarded, 28% moderately retarded, 32% severely retarded, and 27% profoundly retarded.

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*Hudson State School is a fictionalized name.

The incidence of additional handicapping conditions other than mental retardation did not change substantially during the period under study. For example, the most common additional handicap, affecting nearly a quarter of the residential population in 1972, was epilepsy. In 1974, 29% of the population were epileptic. Other common additional handicaps were mobility and psychiatric problems, each affecting about 18% of the residential population. The 1975 residential population's additional handicaps did not vary from those reported for 1974. For both the period under study and in 1975, the vast majority of residents at Hudson State School were court committed. Approximately, 80% of the School's residents were originally admitted to the School through court commitment. 15% of the population was originally admitted by parental or guardian authorization, while the remaining 5% were voluntarily self-admitted to the School.

While the number of Hudson staff has not substantially increased since 1972, per capita expenditures have risen. In 1972, the per capita expenditure was a reported $6,424. There was a 24% increase in 1973 to $7,948 and another 11% increase in 1974 to $8,814. Per capita expenditures for 1975 showed a 22% increase from the preceding year, to a reported $10,726.

## 1.2 State Context

### 1.2.1 State and Institution's Deinstitutionalization Policies

There is no statewide policy as such which sets forth specific goals relating to the deinstitutionalization of mentally retarded citizens. Through periodic review legislation and with the establishment of the community mental health center system, however, the state has begun to recognize and provide for deinstitutionalization requirements. Staff at Hudson noted that the State Department of Mental Health was in 1975 completing a comprehensive recodification of existing statutes related to mentally retarded persons which would be submitted to the Legislature during its next session.

The Hudson State School has developed its own policies and guidelines for client release, largely dealing with the issues of who should be considered for release and why, and the kind of support plan that should be operable in the community. For 1972 and 1973, Hudson had no specific goal for the number of clients to be released other than to release as many clients as were ready for community placement. During 1974, a list of individuals recommended for placement was created, and there was a formally stated goal of 80 releases (20% of the institution's total population). That goal was directed at the reduction of inappropriate institutionalization, and also reflected an institution philosophy encouraging utilization of less restrictive environments wherever possible.

## 1.3 State Legislation Relating to Deinstitutionalization

### 1.3.1 The Right to Education Law and Its Impacts

Through legislation passed in 1972, the state required public school superintendents to accept responsibility for the education of all handicapped children until they reach the age of 21; this legislation was to be fully implemented as of October, 1982. The law was in initial stages of implementation in 1972 (affecting less than 10% of all school-age clients) and in partial implementation in 1973 and 1974 (between 11% - 85% of the school-age clients were served). Beginning in 1972, the state provided funds to all school districts for the establishment of comprehensive plans to meet the special needs of the handicapped. State policy mandates that, whenever possible, those children requiring special education should attend regular classes and be integrated with the rest of the student body; separation of handicapped children, or their removal from regular classrooms, is allowed only after it has been proven that regular schooling is infeasible.

According to Hudson staff, the right to education legislation had impacts in a number of areas, including the following:

- Increase in the number of clients served by educational and pre-release programs at Hudson;
- Increase in the quality of educational and pre-release programs at Hudson (better teacher-student ratios);
- Increase in the number of released clients followed up by Hudson on a regular basis;
- Increase in the number of clients participating in educational programs in the community;

- Increase in the number of clients receiving other services and participating in other programs in the community;
- Increase in the number of clients released by Hudson into community settings;
- Decrease in the readmission rate of released clients;
- Increase in the number of severely handicapped clients placed in the community;
- Increase in the number of clients placed in family or foster homes;
- Decrease in the age of clients placed in the community;
- Increase in the number of clients placed in nursing homes or other institutional settings; and
- Increase in community awareness and responsibility for mentally retarded persons.

### 1.3.2 The Periodic Review Law and Its Impacts

Legislation impelemented in the state provides for the periodic clinical review of each client every six months in order to document changes in condition and treatment requirements. (Hudson had a previous administrative policy, established in the early 1960's, which provided for the assessment of each client on an annual basis.) During 1972-1974, the six-month periodic review process was in a state of full implementation, covering from 85%-100% of Hudson's residents.

The impacts of the periodic review legislation, according to staff at Hudson, have been much the same as the impacts of the right to education law; these impacts are listed in the preceding sub-section. In addition, staff feel that the periodic review legislation has increased the number of clients placed in group homes and semi-independent living situations and has enhanced the development of a sheltered workshop program.

## 2.0 CLIENT ASSESSMENT PROCEDURES

Regular comprehensive assessments of each client at Hudson are accomplished through meetings of a multi-disciplinary team of Hudson staff with a community mental health agency representative and the parents of clients. In some cases, clients themselves participate as well. These reviews take place in two 3-½ hour sessions per week; a total of about 10 clients are reviewed weekly. Assessments are conducted in the areas of medical, social, psychological, educational, and vocational needs and progress. The client's residential status is then considered in terms of her/his need for continued institutionalization, or the possibility of an alternative care plan in the community with necessary support services.

Staff at Hudson report that target clients released in 1972-1974 were all assessed at least annually along the dimensions of medical, psychological, educational, vocational, and social development. For all three years, the following staff were involved in the assessment of released clients: unit directors, psychologists, social workers, nurses, vocational rehabilitation counselors, direct care staff, educators, speech and physical therapists. The superintendent was involved only in 1972, and the involvement of physicians and volunteers was discontinued in 1974. In that year, occupational therapists were added to the assessment team.

In addition to Hudson staff, social workers from community mental health agencies participated in some of the assessments of clients released in 1972 and 1973, and in almost all of those conducted for clients released in 1974. A little less than one-third of the families of target clients released in 1973 and 1974 participated in regular assessments, and approximately one-third of the released target clients in all three years reviewed and discussed their assessment results with staff. Target clients released in the three years also participated in the decisions which eventually resulted from their reviews by asking for alternative placements or discussing suggestions for alternative placements.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction

There are currently four pre-release programs in operation at Hudson State School, all of which were available to clients released in 1972, 1973 and 1974. Two of these -- the Pre-Release Dormitory and the Pre-Placement Cottage -- are residential programs, and two -- Work Activities and Work Training and Evaluation -- are vocationally oriented programs.

### 3.2 Program Descriptions

#### 3.2.1 The Pre-Release Dormitory

The Pre-Release Dormitory is a separate residential program primarily for pre-adolescents, adolescents and young adults. It presently serves 24 clients, ages 8 through 20. The program is designed to promote social maturation and provide education which will eventually lead to community placement for clients. Individuals are admitted to the program after recommendations by the periodic review team.

The Dormitory operates under the basic philosophy that by encouraging clients to control their environment through taking responsibility for maintaining their own living spaces (including a bed, a desk, and a closet), the clients will build their self-confidence. The Dormitory uses an ongoing verbal contract system, in which clients receive positive reinforcement if they follow mutually agreed-upon programs.

In a typical day in the Pre-Release Dormitory, clients are awakened, then wash, groom and dress themselves and clean their rooms before breakfast and school. Some residents attend special education classes in the community, while others are in the academic department at Hudson. When clients return from school at noon, they help with lunch (setting tables, serving, clearing and washing dishes), and then run errands as time allows before returning to school for the afternoon. After the evening meal, stuctured activities usually take place in the recreation room, which is equipped with a pool table, televisions, woodworking tools and work behcnes, and arts and crafts materials and equipment. Lights go out at 9:30 p.m.

According to staff, all clients in the Pre-Release Dormitory receive training in the following skill areas:

- Self-help skills (individual needs are identified and habilitation plans geared to these needs are formulated);
- Personal hygiene and basic sex education;
- Housekeeping;
- Behavior management (inappropriate and socially unacceptable behaviors are eliminated through a combination of the contract system and behavior modification techniques);
- Pre-academic skills (skills are taught at school while the client is living in the Dormitory);
- Academic skills (traditional, formalized approaches are used in a structured academic setting);
- Using community resources (clients take field trips, go skiing, make shopping trips, and attend movies and community events); and
- Money management (clients are encouraged to save, to make their own purchases at the "canteen," and to learn to make change).

During 1972-1974 approximately 10% of the 157 released target clients participated in the Pre-Release Dormitory. The primary staff in the Dormitory in 1972-1974 were attendants and aides. A wide range of professional staff worked in the Dormitory as well, including the superintendent.

Hudson staff indicated that more residents involved in this program could have been placed into the community during the 1972-1974 period. However, two impediments existed: (1) When suitable school programs existed, suitable residential placements did not; and (2) when suitable residential placements were available, special education classes were filled to capacity.

### 3.2.2 Pre-Placement Cottage Program

The Pre-Placement Cottage Program is a separate residential pre-release program which prepares clients aged 16-25 years for community living; the program operates in conjunction with the Work Evaluation and Training Program which is described below. This total habilitation process was specifically designed to evaluate and develop functional skills in community living and interpersonal relations (in the Pre-Placement Cottages) and in basic work skills, work adjustment, and work habits and attitudes (in the Work Training and Evaluation segment). The program approximates the community as closely as possible in order to condition clients to the demands of social and vocational life in the community.

The program is designed to be time-limited, with clients staying from 6 to 18 months, after which they either move into the community (if they are functionally and socially ready, and if alternative placement is available), or into other units within the institution (if they are not able to master skills and/or if community placement alternatives are not available). There are two cottages, one for men and one for women, each serving 19 clients who have private or semi-private rooms and who share in some cooking and housekeeping tasks, as well as various house activities.

During a typical day in the program, clients awaken, make their own breakfast, and report to their work station. Insofar as possible, clients work an eight-hour day. Tasks of meal preparation are shared and rotated. During the evenings and on weekends, they are likely to participate in a social/community experience, using community educational and recreational resources and making visits to job sites. Group meetings with cottage parents are also held during the evenings.

Residents of Hudson are chosen for potential participation in the Pre-Placement Cottage Program through the periodic review process; applicants are then screened by the vocational rehabilitation unit associated with the School. In addition to Hudson clients, mentally retarded people directly from the community are served by the Pre-Placement Cottage Program. These people come to the program by way of recommendations and referrals from local rehabilitation counselors throughout the state.

Approximately 20% of the target clients released during 1972-1974 participated in the Pre-Placement Cottage Program. Staff report that all of those participating received training in the skill areas listed for the Pre-Release Dormitory Program. In addition, they develop skills in the areas of meal preparation, preparation for job applications/interviews, specific job skills, and on-the-job training; work and job-oriented skills are learned through the concurrent Work Evaluation and Training Program.

Direct care staff (cottage parents) spend the most time working with clients in this program. Other staff categories who work with clients in the program, listed according to the amount of time spent, include the Superintendent of the institution, unit directors, vocational trainers, department heads, psychologists, speech therapists, nurses, physicians, psychiatrists and volunteers. (The Superintendent's participation decreased in 1973 and 1974.)

### 3.2.3 Work Training and Evaluation Program

The Work Training and Evaluation Program involves on-campus "work stations" and on-the-job training which is directly transferable to community situations. Trainees are evaluated for interest, attitude, aptitude and skills after training in the areas of maintenance, housekeeping, kitchen work, laundry operations, and orderly/nurses' aide. Depending on the evaluation results, clients may move into a community job (while remaining in the Pre-Placement Cottage) or receive formal on-the-job training as an extension of regular training.

### 3.2.4 The Work Activities Program

The Work Activities Program, which serves clients aged 16 and over, is not designed strictly as a pre-release program, although it often functions as one. It is a sheltered workshop program on the institution grounds which promotes social normalization through vocationally oriented tasks. The emphasis is on success in tangible matters without undue stress -- actual production is important only insofar as it lends to the individual's development of self-confidence and feeling of usefulness and productivity. Clients learn to work successfully with their hands, to become self-motivated, to be less dependent and to have greater control over their environment.

Clients participating in the Work Activities Program are given set assignments. There is a hierarchy of jobs, so that clients may be "promoted" or "demoted" according to their success or failure in the performance of tasks. The regular workday in this program is five hours long, including 2-½ hours each in the morning and afternoon. Participants may leave during the day for medical or dental appointments, and may rest at the workshop if required. They are paid on the basis of their production, averaging from $2 to $9 per week. All profits from program operations go to client pay and to shop supply funds.

Clients enter the Work Activities Program either through self-selection, through the periodic review process, or through recommendation of dormitory staff, school staff, or institution psychologists. They may also enter the Work Activities Program through a pre-vocational program which uses short-term projects as a way to increase attention span, enable clients to manipulate objects with their hands, and do small assembly tasks.

The Work Activities Program teaches self-help skills (in terms of dependency reduction). Behavior management is attained in an environment which is conducive to social/vocational achievement, using accomplishment of tasks as reinforcement of desired behavior. Pre-academic and academic skills are learned through performance of various tasks and through the use of an assortment of devised and purchased tools. Clients may be placed on various projects in order to determine task preferences, preferred working conditions, level of productivity, and possible job options. Such projects include laundry bag folding, paper salvage (removing excess paper from cylinders), hooked rug assembly, shearing fuzz from wool fabrics, stickering business forms for deletion, and loom operation for the production of stair treads or placemats.

Sixty-three percent of the 67 released target clients in 1972 had participated in this program; this percentage increased to 70% of the 43 target clients released in 1973 and 77% of the 47 target clients released in 1974. The unit director spends more time working with clients in this program than staff in any other category. Other staff involved, in order of time spent include direct care staff, instructors, social workers, nurses, physicians, psychiatrists, and vocational rehabilitation counselors.

## 3.3 Overall Characteristics of Pre-Release Programs

According to the Director of Community Services, the major strengths of Hudson's pre-release programs lie in three areas:

- The administration is interested and dedicated;
- The staff has a definite sense of direction in relation to the setting of time-specific goals for clients, laying the groundwork for future learning, etc.; and,
- The programs build motivation and reduce dependency, thus giving them meaning beyond their primary impact.

The major weaknesses of the pre-release programs include insufficient staff and space, and the problem of isolation from the community. Efforts at improving the programs include raising the quality of the living units (reduction of noise level and unit size, etc.) and placing greater emphasis on behavior modification and individualized habilitation efforts. There is planning for more community involvement and more frequent use of community resources as well.

Staff at Hudson also report that plans are being discussed with the Vocational Rehabilitation Unit Staff to possibly expand the pre-placement concept into several metropolitan areas. These plans include on-the-job training sites combined with small (6-8 person) group homes with more emphasis on individuals interfacing on a daily basis with the general community. Such a program would provide a necessary alternative, Hudson staff feel, to the existing pre-release programs which, because of the institution's geographical location, cannot fully simulate actual community life.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

From 1972-1974, the release process for all target clients typically started with a status assessment by an interdisciplinary team, which arrived at a recommendation for alternative placement, and formulated a proposal for an alternative care plan (e.g., attendance at regular school, provision of speech and physical therapy, etc.). Parents of the client were usually involved in formal placement recommendations. The typical target client was released to a trial placement situation, and was followed up by Hudson's social service staff and by the local Community Mental Health representative. When the trial period ended, the client was followed up solely by the Community Mental Health representative.

Family-initiated releases differ slightly from institution-initiated releases in that a client is sometimes formally discharged from Hudson to the family. The family has a choice whether or not to receive post-release services. In the case of a client who initially came to Hudson through voluntary admission(i.e., either family- or client-initiated admission), Hudson is required to release her/him within 14 days after a request for release is received.

The three main criteria for determining whether a client is ready to be placed in the community are: (1) functional level of the client; (2) the availability of residential and program opportunities in the community; and (3) the existence of local social services. The majority of clients released during 1972-1974 were released on extended visit status. Extended visit status may be retained indefinitely by the client.

### 4.2 Factors Affecting Release

Clients who are considered easiest to place are those with well-developed self-help skills and functioning ability. While they typically need little supervision, those easiest to place usually require a sheltered working environment because there is a lack of appropriate job opportunities in the competitive market. Easily placed clients usually have no serious medical or psychiatric/emotional problems.

Staff consider clients to be difficult to place if they are severely or profoundly retarded and multiply handicapped. Other problems in placement are clients with emotional/behavioral difficulties. In addition, because of a lack of community nursery programs, very young clients (e.g., four years old) are often difficult to place.

The fact that certain "types" of clients are placed in any given living situation is in most cases simply a function of matching client needs for care and training to facilities, programs, and personnel available. Clients who are placed in natural homes may have any type(s) of handicap at any level of severity; they are usually older children or young adults. Since foster homes tend to take children who still require educational placement, placement is contingent on locating a classroom situation for the client.

Group homes take clients who require a quiet, sheltered environment with minimal activity in the community; most activities take place within the home. Although they are not presently geared to the provision of education and transitional services that would make it possible for a client to move into a less sheltered and less restrictive environment, it is hoped that group homes in the area will eventually serve this purpose. Group homes are currently the type of placement most likely to accept those clients who are otherwise difficult to place.

Another type of setting, called a community boarding home, is frequently used as placement for adults some of whom have been at the Hudson State School for many years, but who have functional potential for living in the community. The community boarding home utilizes family residences and family care, and provides a sheltered setting which is still a part of the whole community.

The boarding home and group home concepts are predicated on a routine that is as similar as possible to the "normal" lifestyle of the community--in other words, living in a house that is no different from other houses and leaving the house Monday through Friday to attend an activity center or day program where a variety of experiences take place.

Individuals who are able to manage their own affairs, both socially and vocationally, and who have a minimal need for supervision, usually do well in a community-boarding home. Those who are able to manage without supervision, and who feel comfortable in approaching agencies and participating in community programs, are likely to be found in independent living situations.

### 4.3 Client Status Upon Release

Technically, the fact that an individual is residing at the institution has no effects on his/her legal power to marry, vote, enter into an employment contract, secure legal services, leave the facility, or refuse medical or other services offered by the facility. In practice however, Hudson staff report that clients who marry are soon discharged from the facility. Moreover, Hudson staff report that residents are not usually included in the electoral process and that it is not always possible for clients to effectively articulate refusal of services. After placement in the community, no legally limiting factors operate on the client's options to marry, vote, etc.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

Following approval of a placement/program site and after a client has been released by Hudson into the community, a social worker and a rehabilitation counselor alternately provide follow-up with a monthly visit. Periodic visits are also made by Hudson's Director of Safety and Community Living to inspect the client's living situation for compliance with safety standards. Staff maintain contact with the client through occasional phone calls and through regular visits to the client's home and work or day activity settings. In addition, the clients may make visits to the institution as the need for services arises.

Clients are also followed-up by the local community mental health agency and the Visiting Nurse Program, which is sponsored by the Home Health Care Agency. On the average, staff from Hudson report, client follow-up takes place at least once a month. All clients released from Hudson during 1972-1974 received initial follow-up from the institution, and subsequent follow-up from community agencies.

### 5.2 Support Services Provided to Clients

#### 5.2.1 Agencies with Continuing Responsibilities for Client's Welfare

The institution has primary continuing responsibility for an individual's well-being if she/he is on extended visit status. If the client has been formally discharged from Hudson, the agency with primary continuing responsibility for the individual (including provision of continuing education, follow-up services, and securing any further necessary changes in placement) is the local community mental health agency. Clients on extended visit status have the right to return voluntarily to Hudson without regard to waiting lists or waiting periods, and the institution's Director has the legal power to return individuals released on extended visit status to the institution involuntarily.

#### 5.2.2 Types of Support Services Provided to Clients

Support services provided to clients by the institution after their release include:

- Social services (personal and job counseling, financial aid, planned social activities, provision of clothing and gifts);
- Medical care (treatment for all medical problems, preventive medicine, dental services, provision of health aids such as glasses and hearing aids);
- educational programs (EMR and TMR classes, personal skills training);
- Vocational training (job search service, on-the-job training, job orientation, employer and client counseling); and
- Recreational programs (dances, games, picnics, movies, outings, and vacations at summer camps).

All clients released from the institution in 1972, 1973, and 1974 received social services and medical care, and the majority also participated in recreational programs. Approximately half of the clients were involved in educational programs. Relatively small percentages of clients in each year participated in vocational programs. Social services and vocational training were provided monthly, or as required, in all three years. Recreational programs were offered weekly, educational programs continued throughout the academic year, and medical care was provided as required.

In regard to those support services provided by the institution, the following staff are involved, ranked according to the amount of time spent: social workers and vocational rehabilitation counselors (who spend equal amounts of time), Coordinator of Community Services, Superintendent, unit directors, nurses, physicians, psychologists, physical therapists, volunteers, and psychiatrists. Community mental health agencies are involved in the provision of all types of support services. Social services and medical care are available from the institution as well, and the State Department of Vocational Rehabilitation provides social services, medical care, educational programs, and vocational training. In addition, the Visiting Nurses are involved in the provision of preventive medical care, referrals to physicians, dentists or hospitals, and the follow-up thereafter.

The amount of social services provided is considered by Hudson staff to be sometimes adequate, sometimes inadequate. Similarly, the medical care provided to released clients falls somewhere between adequate and inadequate in regard to quantity, e.g., unless the released client has enough personal funds, she/he must return to the institution for services. The educational programs and vocational training provided are felt to be adequate in amount, and the recreational programs are seen as inadequate. All clients released into all types of community settings on extended visit status have received some follow-up support services. However, staff from Hudson State School feel that these support services are currently inadequate.

## 5.3 Support Services Provided to Those Responsible for Released Clients

During 1972, the training provided to client families (including house managers and staff) to prepare them to work with clients was rudimentary, and was provided primarily by the institution social worker. Training focused on dealing with individual clients' needs, weaknesses, and strengths, on obtaining medical and other support services, and on meeting medication requirements. In 1973 and 1974, an expanded training process evolved: attempts were made to formalize training in classes to be held in a central facility in the community, and a broader educational approach was taken. Client families were encouraged to make greater use of community resources, to use better care and record-keeping techniques, etc. During all three years, family education was provided to approximately 40% of client families, on a bi-annual basis.

The Hudson State School has also provided training to teachers and employers of released clients. This training is provided on a one-to-one basis by the social worker to vocational rehabilitation counselor. The purpose of the training is to acquaint employers and teachers with individual client's strengths and weaknesses and problems relating to school or work in the community. The training also helps to assure the employer or teacher that the client will continue to be reviewed and counseled, with back-up for problem-solving as needed.

## 5.4 Institution's Assessment of Released Clients' Adjustment to Community Living

In making attempts to assess how well released clients are adjusting to life in the community, the State School gathers reports from the clients themselves, and from social workers, teachers, parents, nurses, and community activity center staff. If a client is functioning with greater ease than when s/he left Hudson, s/he is seen to be adjusting to community life. According to this criterion, Hudson staff feel that approximately 12% of the clients released during the period under study are adjusting extremely well, 11% very well, 55% moderately well, 10% fairly well, and 12% poorly. (Most of the clients in the latter category have been readmitted to Hudson.)

Clients who have made an excellent adjustment to community life are characterized by Hudson staff as individuals who have profited from a less restrictive environment and who have made use of the available activity programs, job opportunities, and community resources in general. These clients are also people in relatively good health who possess adequate self-help and interpersonal skills. They may be at mild, moderate or severe levels of retardation as well.

Clients who have made a moderate adjustment to the community are those who are functioning successfully in the community, but who have unresolved medical and emotional problems which complicate interpersonal relationships at their residence or day placement.

Clients who have adjusted poorly or who have not adjusted to community living are characterized by institutional staff as individuals who have medical or emotional problems beyond their immediate control or that of the supporting community agencies. Staff feel that these clients may have chronic behavior problems which inhibit their ability to profit from the community experience at this time. Hudson staff also point out that poor adjustment may be a result from premature release and suggest that more therapeutic settings are needed in the community such as training homes which bridge the gap between the clients' institutional dependency and the community's expection of the released clients' independence from the institution.

## 6.0 RELEASED CLIENT PROFILE

As stated in Section 1.0 , clients released between 1972 and 1974 were grouped into two categories: target and non-target clients (see Glossary). In this section, information is presented first on the overall released population from Hudson State School during this time period, and secondly, on released target and non-target clients separately. Since the focus of this study was on target clients, more information was collected for this group than on non-target released clients.

Hudson State School released a total of 314 clients between 1972 and 1974. In 1972, 127 clients were released, or 24% of its residential population for that year. In 1973, another 101 clients were released, or 21% of its population. Finally, in 1974, 86 clients were deinstitutionalized, representing 19% of its population for that year. The majority (83%) were adults between the ages of 18 and 40 years. For all three years, approximately 55% of the released clients were males.

Approximately 37% of the released clients from Hudson were mildly retarded. Thirty-eight percent were classified as moderately retarded, 16% severely retarded, and 9% profoundly retarded. The most common additional handicapping conditions found in the released clients (other than mental retardation) were deafness (about 8%) and mobility problems (approximately 15%). Other handicaping conditions affecting released clients were epilepsy (8%) and psychiatric problems (4%).

Nearly half of all released clients were placed in group homes upon release from Hudson State School. Almost a quarter of the released clients were placed in independent living situations. Natural/adoptive homes received almost 9% of the released group, while foster homes were the placement for 10% of the clients. Finally, 7% were placed in nursing facilities and 1% were placed in other institutions.

## 6.1 Characteristics of Target and Non-Target Clients

Of the 314 clients released from Hudson, half were target clients for the purposes of this study. Of these target clients, 67 were released in 1972, representing 13% of the institutional population for that year. In 1973, 43 target clients were released, or 9% of Hudson's population. The remaining 47 target clients were released in 1974, representing 11% of the institutional population. Of the target clients, 19% were children and/or youth (ages 6-18) and the majority of clients were male during all three years.

Most of the target clients were considered to be mildly (47%) or moderately (32%) retarded. Less than 20% were severely retarded and 3% were profoundly retarded. The levels of retardation among the children released tended to be more severe than for the adults. The largest group of children released according to level of retardation was severely retarded (38% of the children). For adults, the largest group by level of retardation was mildly retarded (53% of the target adults).

Very few of the target clients released during the three-year period had handicapping conditions in addition to mental retardation. Among those that did, the most common additional handicaps were deafness (about 7% of the target clients) and mobility problems (about 4% of the target clients).

For each year. approximately 80% of the target clients released had initially been placed at Hudson through court commitment; the remaining 20% came to the institution through voluntary self-admission, or through admission by authorization of a parent or guardian.

Of the 157 non-target clients released from Hudson during the period under study, 60 were released in 1972, 58 were released in 1973, and 39 were released in 1974. Non-target clients did not differ from the target clients in terms of age ranges of those released or proportions of males to females. However, non-target clients did vary from the target population in terms of levels of retardation. Nearly 30% of the non-target clients released were either severely or profoundly retarded. Forty-four percent were moderately retarded while 27% were mildly retarded.

Non-target clients also had more additional handicaps other than mental retardation than target clients. Almost 20% of the non-target released population experienced mobility limitations. Nine percent were considered to have psychiatric problems and another 9% were epileptic. About 8% were deaf and staff report that nearly one-half of all non-target clients had other unspecified secondary handicapping conditions.

The circumstances of initial commitment to Hudson for the non-target clients did not differ significantly from the target population.

### 6.2 Skills of Target and Non-Target Clients Upon Release

In most cases, the skills of released clients either remained constant or decreased slightly from 1972 to 1974. Over the three year period, all clients released had skills in behavior management, and the large majority possessed self-help and pre-academic skills. Approximately 60% of the clients released in 1972 had housekeeping skills, but this decreased to 40% for those released in 1974. From 15%-25% of the clients released from 1972-1974 also possessed skills in meal preparation, academics, use of community resources, use of public transportation, money management, prepration for job applications/interviews, and specific job-related areas. In all but the last three areas, client skills declined somewhat over the three-year period. Very few clients in any of the three years had knowledge of birth control techniques and human sexuality.

Information on the specific skills possessed by non-target clients was not gathered.

### 6.3 Residential and Day Placements of Released Target and Non-Target Clients

For target and non-target cleints, the most frequent residential placement upon release was to group homes. Forty-two percent of the target clients and 56% of the non-target clients were so placed. All the clients placed in these group homes were adults. The next most common placement for target clients was to independent living settings, where again, all the clients so placed were adults. For non-target clients, nursing homes were the second most common placement (for 14% of the non-target clients). Foster homes received about 12% of both the target and non-target clients and all the clients placed in foster homes were children. Natural/adoptive homes received about 9% of both the target and non-target groups.

Less than a quarter of all released clients visited their prospective residential placement prior to their release. About the same number visited their prospective day activity programs prior to their release.

The most frequent type of day placement for the target clients was to day activity centers, accounting for 2/3 of the 1972 placement and almost 3/4 of the 1974 placements. The second most common day placement was to full-time competitive employment. During the three-year period, small numbers of clients were also released to workshops and public school programs. Similar information on the day placements of non-target clients was not collected.

### 6.4 Readmissions

Readmission rates varied somewhat for target clients released from the Hudson State School. Fifteen percent of the 67 target clients released in 1972 were subsequently readmitted to the institution. Five percent of of the 43 released target clients in 1973 and 11% of the 47 released target clients in 1974 were also readmitted. Most of the clients readmitted from 1972 releases and all of those from 1973 to 1974 releases were adults. The majority of clients readmitted from 1972 and 1974 releases were males which are of those readmitted from 1973 releases were females.

The majority of clients readmitted from releases during the three-year period had been in the community for six months or less prior to readmission, although some 20% of those readmitted from 1974 had been in the community for six months to one year. All were on extended visit status at the time of readmission. For all three years, the majority of readmissions were from group homes, although 20% of those readmitted from 1974 releases had been in independent living situations.

For the most part, reasons for readmission of target clients were related to behavioral/adjustment problems such as personality conflicts, character disorders, inability or refusal to follow guidelines, lack of required social skills in job situations, and medical problems.

Information of the readmission rates and causes for non-target clients was not obtained.

## 7.0 PROFILE OF STUDY GROUP CLIENTS

Of the 157 target clients released from Hudson State School during 1972 and 1974, 34 or 22% were interviewed during July and August of 1975, and are referred to as the study group (see glossary). In this section, information will be presented on the study group which was collected from institutional staff, records, the client study group, and his/her family, social worker, housemanger, or other contact persons interviewed about the client. The information presented is not intended to serve as a validation of the information collected from Hudson State School nor as a "follow-up" on the study group clients. Rather, the intent is to give a generalized overview on the types of clients released from Hudson who were interviewed along with descriptive information on the services and training received since release, the types of problems encountered as perceived both by the client and his/her contact person.

### 7.1 Study Group Characteristics

The age range of the study group was from 7 to 40 years, with an average age of 22 years. The vast majority of the study group was white (94%). Almost half of the study group was mildly retarded (44%), while over a third were moderately retarded (35%). Less than 10% were severely retarded, and 3% were profoundly retarded. The remaining 9% of the group were of an unrecorded level of retardation. The most common additional handicaps amoung the group other than retardation were speech impediments (35%), mobility limitations (18%), and psychological problems (15%).

### 7.2 Residential and Day Placements

#### 7.2.1 Residential Placements

While nearly half the study group released from Hudson State School between 1972 and 1974 were initially placed in group homes (41%), less than 10% were in such settings at the time of the interviews. In addition, whereas about 15% of the study group were initially placed in foster homes, nearly half (44%) were living in foster homes when interviewed. Nearly a quarter (24%) of the study group was initially placed in natural/adoptive homes and a similar proportion (26%) were in such settings when interviewed.

### 7.2.2 Day Placements

According to the families of the study group members, over a third (38%) of the clients were initially placed in either competative employment or sheltered workshop situations. Another third (32%) of the clients were placed in day activity programs, and about one-fifth (21%) of the study group clients were initially placed in school programs. One client was not initially placed in any program.

At the time of the interview, nearly a third (32%) of the group study members had changed day placements at least once. Slightly fewer than half (41%) of the client were placed in competitive employment or sheltered workshop situations, while a little more than a quarter (29%) were reportedly enrolled in a day activity program. The same percentage (21%) were placed in school programs in the interview period as were so placed initially upon release.*

About 15% of the study group reported that they were not involved in any day program at the time of the interview, the most common reasons mentioned for the lack of a day program were that there were no programs available for the client and that the client was relunctant to participate in a day program.

## 7.3 Institutional Follow-Up

Families of the study group clients were asked if anyone from the institution had follow-up contact with the client after release. Approximately 91% of the respondents reported that there was some follow-up from an institutional staff member. The most frequently stated method of contact was by visitation to the clients residence. Other methods of follow-up were by phone conversations with the client, and by contact through the client's community social workers or someone responsible for the client.

The amount of follow-up seemed to decrease over time. Follow-up contact was reported by 88% of the respondents during the first six months after member's release, while only 73% of the respondents reported follow-up contact during the six-month period prior to the interview. This tendency was also found in the frequency of follow-up contact. Respondents reported that during the first six months after release, contact was most frequently made on a monthly basis. However, respondents also reported that the contact during the six months prior to the interview took place most often on a twice/yearly basis.

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*Multiple day placements were possible so that the percentage given exceed 100%.

Family respondents were asked how satisfied they were with the follow-up provided by Hudson State School. Over three-quarters of the respondents (76%) reportedly were very satisfied with the follow-up received. Only 6% said they were dissatisfied, and 9% of the respondents said they were neither satisfied nor dissatisfied with the institutional follow-up provided.

## 7.4 Case Managers and Study Group Clients

Almost all of the study group members (94%) reportedly had a case manager, or someone who was responsible for the clients' well being and for on-going support. However, while virtually all the study group members (94%) reported having a case manager immediately after their release, only about two-thirds (68%) reported having a case manager during the six months prior to the interview. During both time periods, the person most often cited as the case manager was the client's parent or houseparent. Another frequently cited person serving as a case manager was a staff member from the institution during both time periods. About two-thirds of the study group clients reportedly had daily contact with their case managers during both time periods.

## 7.5 Services and Training

### 7.5.1 Services and Training Need

Family respondents were asked about the support services and training needs of the released study group.* The services cited most often an needed but not received by the released study group from Hudson State School were speech therapy (sited by one-quarter of the respondents), legal counseling, and social and/or psychological counseling. The types of training cited most frequently as needed but not received by the respondents were development of motor skills, use of numbers and time, travel skills (getting around the neighborhood) and money management.

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*See glossary for the list of support services and training areas on which information was gathered.

The support services most frequently mentioned by the respondents which they felt they needed but did not receive were support and/or training prior to the client's coming to the residence and consultation for special problems encountered with the released person.

### 7.5.2 Service and Training Use

Family respondents were asked about the study group member's use of various support services and about the clients training in various skill areas. The study group from Hudson reportedly used an average of 4 services since their release. The average number of skill areas in which the study group received training was 8.

Family respondents were also asked about the providers of services and training received by the study group. Of the services used by the study group, almost half (43%) were reportedly received from a community agency, while about one-fifth (20%) were received from the community residence in which the client was living. The study group's day programs provided 15% of the services, and a similar proportion (13%) of the services were provided by other sources. Hudson State School reportedly provided 10% of the services used by the clients after their release.

Of the training received by Hudson's released study group, almost two thirds (65%) was provided by the client's community residence. About one-fifth (21%) was provided by the study groups day programs while 9% was provided by community agencies. Respondents also reported that about 6% of the training received was provided by the institution.

## 7.6 Problems

Family respondents were asked a series of questions about the types and degree of severity of various problems which study group members may have experienced since their release from the institution. Family relationships, personal grooming, and medical problems were most often cited by the respondents as being problems for the study group for the most part. Although for the most part these problems were considered to be extremely severe..

Study group members were asked which problems they considered to be the most difficult since leaving the institution. The majority of the clients cited handling social relationships as being a problem for them.

Other problems mentioned were psychological problems, family relationships, and loneliness.

## 7.7 Interviewers Perception of Study Group Adjustment

Following each interview session, interviewers recorded their perceptions about the study group members' adjustment to the community along three dimensions: degree of social isolation, client satisfaction/ happiness with his/her life in the community, and the overall adjustment of the client to the community.

Over 82% of the study group members were perceived as having some or many social relationships in the community. Only 3% of Hudson's released study group were perceived as being very socially isolated, and 12% were perceived as being somewhat isolated. For the remaining 3% of the study group, the interviewers felt unable to determine the degree of social isolation.

Almost two-thirds (65%) of the study group were perceived as being very happy or contented with their lives in the community. About 18% were perceived as somewhat happy with their current life while 6% were seen as either somewhat or very unhappy in the community. The client's happiness in the community could not be assessed for about 12% of the study group.

Finally, interviewers recorded their perceptions about the overall adjustment of the study group members to the community. Over two-thirds (70%) of the clients were perceived as being well adjusted to life in the community, while only 6% were seen as being poorly adjusted. Nearly 12% of the study group was considered somewhat adjusted to the community, while interviewers could not assess client's adjustment in the community for 12% of Hudson's released study group.

# CHAPTER 8.0: POLK STATE SCHOOL AND HOSPITAL

## 1.0 INTRODUCTION

### 1.1 Overview

Polk State School and Hospital occupies 2000 acres of land in a small town some 80 miles from a major metropolitan area in the East. It was first established in 1897 as a "state institution for feeble-minded." During the early years of its operation, much of the institution's land was used for farming, and because the facilities included horse and cow barns, a bakery, a power house, a cold storage building, and a dam which held back "a sufficient body of water to furnish a full supply of ice for the institution", it was quite nearly a self-contained operation during those years. Polk was mandated to serve 30 counties in the state, and its client population at the end of its first year of operation totalled 349.

The first annual report referred to two children who were discharged that year in a tone of mild disbelief as children "whose mental condition had so greatly improved that their parents considered further institution care and training unnecessary." One of the residents admitted when the doors of the facility opened is still there, 78 years later, with a reputation for being an avid sports fan.

Polk State School and Hospital currently serves 14 counties and has a resident client population of about 2,300 (which represents one-quarter of the state's institutionalized mentally retarded population). While it is no longer functionally independent of the outside community, its site has fostered and supported a social insularity which is now becoming somewhat of an issue. With backup from the State Department of Mental Health/Mental Retardation, Polk State School and Hospital is making an effort to move clients into the community and to create a public awareness of its residents as part of the whole community.

The institutional population at Polk State School and Hospital has decreased in recent years from approximately 2,870 residents in 1972 to about 2,700 residents in 1973 (a 6% reduction) and was reduced by another 7% in 1974 to 2,500 residents. The current population (as of the fall of 1975) was about

2,300 residents, representing another 9% reduction. About 44% of the population was female in each of these years. The age range has shifted slightly, with 18% of the population under age 19 in 1972 while by the fall of 1975, about 14% of the population was in this age range.

The distribution of residents according to levels of retardation has shown slight changes since 1972. In that year, 13% were classified as mildly retarded, nearly a quarter were moderately retarded, 31% severely retarded and 32% were profoundly retarded. In 1974, only about 9% were mildly retarded, 22% moderately retarded, a third were severely retarded, and 36% profoundly retarded. Current levels of retardation were substantially the same.

Many of Polk's residential population during the period under study had other handicapping conditions in addition to mental retardation. While there was no marked change in the percentages of residents with specific conditions, more than a quarter were epiletic and/or had mobility problems. Less than 5% were considered to have psychiatric problems and about 2% were blind and deaf.

The most common means of admission to Polk State School and Hospital was through authorization by parent or guardian (about two-thirds of the residents were so admitted). A little more than a quarter were admitted through court commitment while the remaining 4% were voluntarily admitted.

Overall institutional expenditures rose 14% between 1972 and 1973 (from a total operating cost of $17,873,000 to $20,454,000). During the following year, operating costs rose another 27% to almost $26,000,000. Current operating costs were not available. The number of staff at Polk showed increases as well. There was a 9% increase from 1972 to 1973 (from 1700 to 1850 staff) while from 1973 to 1974, the staff increased by 10% to 2,030 members. Currently, 2,090 staff members are listed, representing another 3% increase. Nearly 46% of the staff across all three years were attendants. Support staff constituted over a third (35%) of the 1972 staff while currently about a quarter (26%) are listed as support staff. Approximately 6% of the staff over the period of study were considered administrators.

## 1.2 State Context

### 1.2.1 States and Institution's Deinstitutionalization Policies

The State Department of Public Welfare's Office of Mental Retardation set forth an "implementation package" for the state's Community Living Arrangements Program which was established in the early 1970s. It includes a prioritized list of living conditions for mentally retarded citizens, a statement of county, regional and state roles and responsibilities within the Program, and a detailed list of regulations, definitions, and expectations for community facilities. As stated in the policy document, living conditions for mentally retarded citizens take the following priorities:

1. Natural home (with outside provision for family training and education, consultative and support services, state and federal financial supplements, and family relief to include short-term resident care, babysitting, and 24-hour care);
2. Adoptive and foster homes (with all of those support services available to natural homes);
3. Community living arrangements (a progressive continuum of alternative community placements, providing specifically for clients of all ages and all levels of handicapping conditions, and for mentally retarded people who have always lived in the community as well as for formerly institutionalized clients);
4. Nursing homes (for aged retarded citizens);
5. The institution ("When there is no other alternative, an institution should be considered as the acceptable living arrangement.")

**The informal deinstitutionalization policy as described by Polk staff is to release as many clients as are functionally and socially able to leave the facility, and/or who have community residence alternatives.**

## 1.3 State Legislation Relating to Deinstitutionalization

### 1.3.1 The Right to Education Law and Its Impacts

As a result of a court decision in a suit brought against the state by an individual, the Right to Education Act of 1971 was passed and became effective in September of 1972. This state law provides for the education of all children aged 6-21, regardless of type of level of handicap. It places total responsibility for the education of handicapped children in the hands of the public schools, who must submit to a court hearing in the event that they intend to exclude any child. The law is implemented through Local Intermediate Units which are geared to special education needs* and through state institutions such as Polk, as well as through special classes in regular public school settings. Staff at Polk reported that this law was partially implemented in 1973 and full implementation occured in 1974.

Partly as a result of the Right to Education Law, the number of clients served in educational programs at Polk State School and Hospital has doubled, and staff report that the quality of educational programs has improved with increased student/teacher ratio, the hiring of proportionately more professional staff, and a more aggressive approach to the educational needs of retarded clients. The number of clients participating in community educational programs has increased from 0 to 360 (the number served through the Local Intermediate Unit), and the number of clients released from Polk State into the community has increased by a factor of 5-10, due to the availability of educational alternatives in the community. Staff report that more young clients are being placed as a result of the Right to Education Act, although the age range of clients placed in the community has not changed.

### 1.3.2 The Periodic Review Law and Its Impacts

While the state itself has no law providing for the periodic review of institutionalized persons, Polk State has an administrative policy which provides for the assessment of each resident's progress and needs at six-month intervals. This policy was established in 1973 for newly admitted clients, and is presently in a stage of partial implementation. It is planned that all residents will eventually be reviewed on this basis.

The periodic review process is seen as a factor in substantially increasing the number of clients placed in family or foster homes, group homes, and semi-independent living situations in the community; in the number of severely handicapped clients placed in the community, and in the number of clients placed in nursing homes and other institutional settings. Because the periodic review process established a system of accountability, it is viewed by staff to be a major factor in facilitating the processes of program development to meet client needs, service referrals, and general better care for clients.

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*One Local Intermediate Unit is located on the Polk State School and Hospital grounds. This community-run facility serves 360 Polk clients directly, and is programmatically responsible for the education of all clients under the age of 21 in the institution. Clients in the program are trained in eating, toileting, and self-help skills in a setting which is as "normalized" as possible.

### 1.3.3 State Litigation Relating to Deinstitutionalization and Its Impacts

In addition to the Right to Education suit mentioned above, the state has been involved in litigation centering on the issue of peonage, and is currently involved in right-to-treatment hearings. Since 1973, as a result of the peonage suit, residents of an institution cannot be forced to work, and they are to receive reasonable compensation for work performed voluntarily. The right to treatment case, which is more concerned with basic living skill training and vocational training than with medical treatment, has been brought against the state by the Association for Retarded Citizens.

## 2.0 CLIENT ASSESSMENT PROCEDURES

Each target client who was released in 1972 was assessed every year through a "social services survey" which focused on the client's physical state and level of handicap, as well as on the training program in which s/he was involved. Staff at Polk report that the survey was conducted regularly, but more for the purpose of maintaining complete records than for identifying possible client or program impact. As a result of the process, all clients received annual social assessments, and the majority received annual medical assessments. A smaller number, approximately one-third, received annual educational assessments, and virtually none received vocational assessments. Psychological assessments were provided to clients on an as-needed basis.

In late 1973, "team unit program staffings" were established as a new means of client assessment. This procedure, which is currently operational, includes reports from all staff involved with a client. It is meant to be a milestone process which updates prior assessments of client strengths, weaknesses and needs, and then develops goals and establishes programs for clients in response to assessment results. In 1973, half of the clients received annual educational assessments; half received medical assessments on an annual basis; and half on an as-needed basis. Some clients received vocational assessments, which were provided annually if at all.

In 1974, medical, psychological and social assessments were provided to all clients on an as-needed basis, half received annual educational assessments, an approximately one-fifth received annual vocational assessments (a larger number than in the previous two years).

Staff participating in the assessment process in all three years included physicians, psychologists, and social workers. In 1973, vocational rehabilitation counselors were added to the assessment team. Those staff participating in assessments in 1974 who had not been previously included in the process were unit coordinators, nurses, direct care staff, educators, occupational therapists, and speech and physical therapists.

Staff report that clients assessed in 1972 and 1973 discussed their assessment results with staff or provided input into the decisions which eventually arose from the assessment process, and very few participated in their assessments in 1974. In 1972 and 1973, no families, guardians, or advocates of clients were invited to participate in regular assessments. Although such people were invited to participate in 1974, very few did. Representatives of community-based service agencies were also invited to participate in assessments in 1974.

# 3.0 PRE-RELEASE PROGRAMS

## 3.1 Introduction

Before 1973, there were no special programs at Polk State School and Hospital designed to prepare clients for placement into community settings. Several pre-placement programs for adults were initiated in mid-1973; to date, there have been no pre-release programs established for children.

## 3.2 Program Descriptions

### 3.2.1 Project 80 and Project 81

Polk State has two residential pre-release programs for clients aged 18-60 years, one for men and one for women. Between 15 and 18 clients are served in each residence at any one time. Although very few of the clients released in 1973 participated in these projects, over half of those released in 1974 did. The primary purpose of this program is to help clients develop the skills necessary for housekeeping and decision-making. Clients are chosen for participation in this program according to their current functioning level. Before officially entering, each client spends two weeks visiting one of the Project residences (two beds are available for visitors) to determine its suitability for the client.

All of the target clients released in 1973 and 1974 who had participated in Project 80 and Project 81 received training in the following areas:

- Personal hygiene (particularly grooming, with emphasis on neatness of dress, hair, and make-up);
- Housekeeping (choosing and purchasing bedspreads, making beds, doing laundry and ironing);
- Meal preparation (planning menus, food shopping and cooking);
- Behavior management (taught through appropriate reinforcement techniques such as denial of priveleges, and through personal counseling);
- Social skills (etiquette and table manners, taught through reinforcement techniques);

- Pre-academic skills (recognition of signs, symbols, and signals, use of telephones, etc. to enable survival in the community);
- Academic skills (basic arithematic and writing, taught by volunteers);
- Use of community resources (shopping trips and visits to community churches and recreational facilities, made by individual clients or small groups who are accompanied by a counselor); and,
- Money management (making change and budgeting)*.

Some of the participating target clients also received counseling in preparation for job applications and interviews, and the large majority of those released in 1974 received some formal sex education (birth control, basic biological facts, hygiene, etc.) through talks and instruction by staff nurses.

During a typical day in Projects 80 and 81, clients prepare their own breakfast and then leave for day placements (e.g., sheltered workshop, community employment, institution employment). On a rotating schedule, two clients stay to do housework at the residences; they prepare their own lunch, and prepare dinner for the entire group. After dinner, clients often attend institution or community activities, and otherwise have free use of their time until curfew/bedtime.

In 1973, teachers/instructors spent the most time working with clients in this program. The next largest amounts of time were spent, equally, by direct care staff, occupational therapists, vocational rehabilitation counselors, and the Superintendent of the institution. Social workers, speech therapists and physical therapists spent smaller amounts of time at Project 80 and 81 in 1973. During 1974, levels of effort were higher for all staff categories except physical therapists (who spent about the same amount of time as in 1973) and the Superintendent (who spent less time than in 1973).

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* Money management techniques are demonstrated through shopping trips into the community. An interesting arrangement has been made to ensure community cooperation in this process: Polk State sets up pre-paid accounts with community businesses, and when clients make purchases with their shopping allowances, the money exchanged is recycled back to the institution.

### 3.2.2 Auxesis and Avante

As part of the Community Living Arrangements Program, the County Department of Mental Health/Mental Retardation has established two residences on Polk State grounds designed to prepare former clients between the ages of 21 and 55 to live independently in the community. Auxesis (for women) and Avante (for men) are each three bedroom residences housing three clients and a counselor who all later move, as a unit, into a nearby community. Clients are placed on extended leave from Polk State before entering these projects, and no institution staff member is involved with the program. Thus the only bond between Projects Auxesis and Avante and the institution is physical proximity. Indeed, for a few readmitted clients, participation in these programs constitutes their entire community experience.

The overall purpose of Projects Auxesis and Avante is similar to that of Projects 80 and 81, except that the former are more goal- and time-specific. The program is designed to prepare residents for semi-independent community living over a period of four months. Approximately 10% of the target clients released in 1974 received training in this program. They were chosen for participation through staff recommendations and a County Mental Health/Mental Retardation screening process. The types of training received by all clients in this program are similar to those provided in Projects 80 and 81, with the addition of job application/interview skills and the use of bank accounts.

During a typical day, clients in Auxesis and Avante prepare their own breakfast and then go to their community work placements (e.g., Goodwill). When they return from work, they share in preparation of the evening meal. After dinner there are house activities or community outings which are usually arranged by the clients themselves, independently or as a group. As has been previously stated, no Polk State staff work with the clients in this program. The resident vocational rehabilitation counselors (who are employed by the state) and the community work supervisors are essentially the only care/teaching/administrative staff involved with clients in Auxesis and Avante.

### 3.2.3 Community Work Placement Programs

Since 1973, Goodwill and a county-operated diagnostic and training center have worked with the institution to place clients in community jobs during the day. Sixteen percent of the target clients released in 1973, and 19% of those released in 1974 participated in one of these pre-release work programs. The programs are geared to the development of work skills and good working habits, social adjustment, and familiarization with work structures and settings. "Work hardening," the ability to work for longer periods of time, is also emphasized. As part of these programs, clients are evaluated in all areas.

Residents are first chosen for participation in the community work programs after evaluations by vocational rehabilitation staff and recommendations emerging from the regular interview process. The large majority of participating target clients received training in specific job skills, through "job sampling" (including, for example, sorting, piecework, and simple assembly tasks) and evaluation of aptitudes and skills Thirty percent received money management training, including cashing paychecks and establishing good budgeting practices. Ten percent of the participating clients also received training in behavior management (through counseling and reinforcement technqiues) and in the job application/interview process (through counseling, as needed).

A Polk State van takes clients to work at 8:00 a.m. and returns them to the institution at 4:30 p.m. Thus, the institution staff who spend the most time working with clients in these programs are the van drivers. Vocational rehabilitation counselors and social workers are the only other staff directly involved in the pre-release work programs.

### 3.2.4 Vocational Program

A very small number of target clients released in 1973 and 1974 participated in a program at Polk State devoted to making pottery. The goal of this program is to develop motor skills and teach technqiues of working with clay. Adult clients are chosen for participation through evaluations conducted by a vocational rehabilitation counselor. A small percentage of the participating clients received training in behavior management (through reinforcement technqiues); about one-quarter received pre-academic skill training (identification of shapes and colors). Some clients worked full days in this program, although most worked shorter hours. While in the program, clients perform various tasks involved in producing pottery; more difficult tasks are assigned as clients' abilities increase. The products are sold on the grounds of the institution, and clients receive a small wage for their work.

### 3.3 Overall Characteristics of Pre-Release Programs

The main emphasis of the pre-release programs currently operating at Polk State is placed on residential training for adults. Clients are generally selected for participation according to potential evidences through regular assessments, and according to the types of community situations available. The pre-release programs provide training in a variety of daily living skills; as clients mature in a program, they are given more responsibility. Prospects for placement are kept in mind, and as placement opportunities arise, clients are released.

As perceived by staff, the major strengths of Polk State's pre-release programs include a high degree of community contact, a physical environment that is small (and that includes individual rooms for clients), and an effective staff with good attitudes.

One of the main weaknesses of the pre-release programs, according to staff perceptions, is that the placement process is too often ineffective; when a resident is developmentally able to move into the community, there may be no placement available, and development may subsequently reach a plateau, or even decline.* Another major weakness of the pre-release programs is that only a small number of top-level clients are served by the programs; expansion of numbers and levels of handicaps served is now being planned. Polk State is presently attempting to improve the effectiveness of the placement process through closer communication with the Community Base Service Units (local offices of the Department of Mental Health/Mental Retardation) which finds placements for clients.

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*The community placement process currently operates through two separate agencies--the Department of Mental Health/Mental Retardation and the institution--both of which make process decisions independently. The Polk State Superintendent expressed a desire to consolidate the administration of the community placement process, so that predetermination of goals for client readiness could be more easily established and matched to timely and appropriate placements.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

According to Polk staff, the three most important criteria used to determine whether a client is ready for community placement are: the client's functional level; the availability of residential placement in the community; and the existence of local and/or county social services. During 1972, clients were selected for release through a screening process which was based on official records; they were then interviewed by placement agencies (e.g., the Department of Mental Health/Mental Retardation, group homes, etc.). The process was basically the same in 1973, although there was more involvement of the Community Base Service Units.

Polk State School and Hospital played a more aggressive role in the release process in 1974; clients were recommended for release by the team program unit staff involved, and county Mental Health/Mental Retardation offices were contacted to start the process which leads to placement. When placement possibilities were identified, clients were interviewed by the placement agencies, and when residential placement and sufficient support services were secured, the clients were released. This process was nearly the same for family-initiated, as opposed to institution-initiated, releases; in other words, release went through the County Mental Health/Mental Retardation office even when no placement search was required.

From 1972-1974, the large majority of client releases were institution-initiated, and most of the clients were released on extended visit status. Extended visit status remains valid for a period of less than three years before automatic removal from Polk State rolls.

### 4.2 Factors Affecting Release

Social services staff at Polk State characterize clients who are easiest to place as those who function well socially, present a fairly normal appearance, are able to exercise good judgment, and are motivated to work. The most difficult clients to place are older residents (problems center on finding a job), those who are emotionally unstable, erratic, and/or given to adverse behavior, and those who have physical anomalies or who are at a lower level of functioning.

While there is no "typical" community setting for clients with any given set of characteristics, clients who are perceived as "difficult to place" are most likely to be accepted into natural homes, adoptive homes, and foster homes (in that order), and are less likely to be accepted into group homes, semi-independent and independent settings.

## 4.3 Client Status Upon Release

The nature of a client's original commitment to the institution (i.e., court commitment, voluntary self-admission, or admission by authorization of parent or guardian) has no effect *per se* on the range of placement options available to a client, although the events leading to commitment or the reasons for commitment may have some restrictive effect on placement options. (For example, if a client was originally committed by the court because he was judged harmful to himself or others, this might limit his options for later placements.) The procedure for placing an individual in the community and the responsibilities to the client which are retained by the institution are the same regardless of the circumstances of original placement at Polk State School and Hospital.

After placement in the community, clients have legal rights to enter into marriage, to vote, to enter into an employment contract, to secure legal services, and to refuse medical or other services offered by the community or by the institution; this is true regardless of release status. Clients have these same legal rights while living at Polk State, but the institution's policies sometimes impose limits; for example, two residents of the institution are not allowed to marry one another.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Agencies with Continuing Responsibility for Clients' Welfare

The Regional Mental Health/Mental Retardation Office is the agency which has primary continuing responsibility for ensuring a client's well-being after release from Polk State, whether the client is on extended visit or discharge status. The institution retains no official continuing responsibility for an individual's welfare after s/he has been placed.

An individual who is out on extended visit status does have the right to return voluntarily to the institution at any time without waiting to be readmitted. The institution director does not have the legal power to return an individual to the institution involuntarily. Although it has no official responsibility toward released clients, Polk State provides medical and dental services, social services, and respite care to former clients as needed; however, staff report that requests for such services are seldom made.

### 5.2 Types of Support Services Provided to Clients

Follow-up for each client released from Polk State is, as has been stated above, entirely provided by the Mental Health/Mental Retardation Base Service Units, on a monthly basis. Social services, medical care, educational programs, vocational training, and recreational programs are similarly available to released clients through the local Mental Health/Mental Retardation Base Service and Intermediate Units.

### 5.3 Support Services Provided to Those Responsible for Released Clients

Polk State provided no training or support services to the families, guardians, or house parents of released clients during 1972-1974. However, during 1974, prospective teachers and/or employers of clients were sometimes given background information on individual clients (e.g., the nature of the client's handicap, what and what not to expect from the client, etc.) and basic training to facilitate working with clients.

## 5.4 Institution's Assessment of Released Clients' Adjustment to Community Living

Polk State has made informal attempts to assess the community adjustment of released clients. The two general criteria cited by Polk staff which are used in the assessment are the nature of interpersonal relationships which a client has established in her/his community residence, and the degree of a client's success at her/his school or job placement. According to these criteria, social service staff at Polk State judge that the majority of clients are adjusting moderately well to life in the community, with a few clients adjusting very well and few adjusting at a low-adequate level.

Clients who have adjusted very well to community life are characterized as being motivated to stay in the community, having good work habits (i.e., they are not easily discouraged), being resilient, showing a fairly normal and neat appearance, having a quiet personality, and having recreation habits which are not too extravagant. Those who adjust moderately well are largely clients who are at a lower functioning level and who display a lower level of maturity. Typically, these clients have occasional emotional problems and require a good base of supervision. Clients who adjust poorly to community life are viewed as displaying a combination of negative characteristics which may include a low level of maturity, low motivation, behavioral problems, (e.g., acting-out episodes, non-adjustment to societal norms), poor interpersonal relationships with people at home and/or work, poor work habits, and poor personal hygiene.

## 6.0 RELEASED CLIENT PROFILE

Clients released from Polk State School and Hospital between 1972 and 1974 were grouped into two categories: target and non-target clients. Target clients were those persons between the ages of 6 and 60 at the time of their release who had resided at Polk for at least two years prior to their release. In addition, target clients were released to community residences other than nursing homes or other facilities serving 100 or more clients. Non-target clients, include those people outside the specified age range and those who were essectially transferred from one institutional setting to another. The focus of this study is on the target clients and thus, more information was collected on this set of released persons than was collected on the non-target clients. In the following discussion, the overall released population during this time period will be described, followed by a discussion of the target and non-target releases separately. (It should be remembered that the distinction between target and non-target clients was made for the purposes of this study and does not reflect an institutional differentiation.)

Polk State School and Hospital staff report that between January 1, 1972 and December 31, 1974 a total of 261 residents were released. In 1972, 110 clients were released, representing 4% of the facilities total population for that year. In 1973, another 83 were released and in 1974 68 were released, accounting for 3% of the institutional population for each of those years. The majority of the released clients were males over all three years and less than 10% were under age 19.

The vast majority of the released clients were either mildly or moderately retarded (45% and 46% of the total group, respectively). Severely retarded clients comprised about 7% of the total group while only 2% were profoundly retarded.

The most common setting for the released population was semi-independent living situations (40%). About a third were released to natural/adoptive homes, about 20% were placed in independent living situations. Less than 10% were placed in either group homes or foster homes.

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*See Glossary for definitions of target and non-target clients.

## 6.1 Characteristics of Target and Non-Target Clients

A little over half of the total released population were considered target clients for this study (56% or 147 clients). In each of the three years of the study, about a third of the 147 target clients were released. Only about 12% of those released were under age 19 and in 1972, nearly three-quarters of the target clients were male. In 1973 and 1974, about half the target clients were male.

Mildly retarded target clients comprised 50% of those released, while another 40% were moderately retarded. The remaining clients were severely retarded (8%) or profoundly retarded (2%). Very few of the clients released had handicapping conditions in addition to mental retardation. Among those who did have additional handicapping conditions, the most common were mobility limitations, epilepsy, neurological disorders, and deafness. The majority of those clients released in 1972 and 1974 had originally been committed as a result of parent or guardian authorization; in 1973, a slight majority of those released had originally been committed by the courts. Very few of those released in any of the three years were originally self-admitted to the institution.

Non-target releases from Polk State School and Hospital did not substantially differ in numbers or in levels of retardation. Approximately 46% of those released during the three years under study were considered non-target clients and the vast majority were either mildly or moderately retarded (39% and 54%, respectively). Severely retarded residents comprised 6% of the non-target group while 1% were profoundly retarded. About two-thirds of the released non-target group were males in 1972 and 1973 while in 1974, three-quarters of those released were male. Only 7 clients were under age 19 (6% of the non-target group).

As with the target group, few of the non-target clients had additional handicapping conditions. Of those who did, the most common were mobility limitations, and epilepsy. Non-target clients did differ from the target group in terms of type of admission to Polk State School and Hospital. About 60% of the non-target clients were originally admitted through authorization by parent or guardian while another 30% were admitted through court committment.

## 6.2 Skills of Target and Non-Target Clients Upon Release

No information on client skills upon release was available for those clients released from Polk State School in 1972. While similar types of training were offered during 1973 and 1974, actual skill development of the clients released in those years indicate a shift in program emphasis: more of the clients released in 1973 had self-help, personal hygiene, and housekeeping skills, as well as pre-academic and/or academic skills, while more of those released in 1973 had developed knowledge and skills in meal preparation, behavior management, human sexuality, the use of community resources, and money management. Specific information on the skill development of non-target clients as opposed to target clients was not obtained.

## 6.3 Residential and Day Placement of Released Target and Non-Target Clients

One-third of the target clients released in each of the three years were released to their natural/adoptive homes. A little less than one-third, all of whom were adults, were released to independent living situations. A small number were released to group homes and semi-independent living situations, and virtually none were released to foster homes.

A little over three-quarters of the non-target clients were released to semi-independent living situations (all of these clients were adults). About one-quarter were released to natural/adoptive homes. Five non-target clients (4% of the total non-target group) were released to independent living situations, while 2 were placed in foster homes and 7 were placed in group homes.

None of the clients released during 1972 and only a small number of those released in 1973 had made visits to their prospective residential placements prior to release. However, a large majority of the target clients released in 1974 had visited their community residential settings before leaving Polk State School. Information on pre-placement visitations made by non-target clients was not obtained.

The day placements of the released clients was unknown for approximately half of the target clients and was not collected for any of the non-target clients. The unknown placements for target clients were arranged by the client's family, the client, or by a community placement organization and thus, did not involve

Polk institutional personnel. Of those target day placements known to Polk staff, the most frequent type in 1972 was to day activity centers; half of the known placements in that year were to such centers. The next most popular type of placement was to workshops, and a small number of clients also went to full-time competitive employment situations.

In 1973, the most popular type of placement was to workshops; over half of the target clients released in that year went to such placements. The remaining known placements were to full-time competitive employment situations. Placements were slightly more varied in 1974, with an almost equal number of known placements to workshops, full-time competitive employment, part-time competitive management, and day activity centers. None of the target clients released during the three-year period had visited their community day placements prior to release.

## 6.4 Readmissions

Of the target clients released in 1972, a little over one-third returned to Polk State or entered another institution. A little over one-fifth of those released in 1973, and a relatively small number of those released in 1974 were readmitted to an institutional setting. The readmitted clients tended to be males over 18 years of age, and most of the clients who were readmitted had spent six months or less living in the community before readmission. Most readmitted clients had been living in their natural homes, in group homes, or in semi-independent living situations directly before they returned to the institution. All of them had been living in the community on "extended visit" status.

A number of target clients (especially among those released in 1972) were readmitted to Polk State at their own request or at the request of their parents. Reasons for client readmissions included medical problems and behavioral adjustment problems. In some cases, community placement was intended to be temporary (e.g., summer employment), and clients simply returned to the institution at the end of the specified period of release. The readmission numbers for non-target clients was not obtained.

## 7.0 FOLLOW-UP ON STUDY GROUP CLIENTS

Polk State School and Hospital released 147 target clients during the period under study. Of these target clients, 55 or 37% were interviewed during July and August of 1975, and are referred to as the study group (see glossary). Five of these clients had subsequently returned to Polk and were interviewed at the institution. In this section, information will be presented on the study group which was collected from institutional staff, records, the client study group, and his/her family, social worker, housemanger, or other contact person interviewed about the client. The information presented is not intended to serve as a validation of the information collected from Polk State nor as a "follow-up" on the study group clients. Rather, the intent is to give a generalized overview on the types of clients released from Polk who were interviewed along with descriptive information on the services and training received since release, the types of problems encountered as perceived both by the client and his/her contact person.

### 7.1 Study Group Characteristics

There was an age range of between 10 and 45 years for the study group released from Polk. The average age was 30 years. Nearly all (98%) were white, 2% black. Almost half (46%) were moderately retarded, 10% were severely retarded and 2% profoundly retarded. There was an unrecorded level of retardation for the remaining 6%. The most common additional handicaps of the study group were speech impediments (20%), psychological problems (16%), and epilepsy (13%).

## 7.2 Residential and Day Placements

### 7.2.1 Residential Placements

The most common initial residential placement of Polk's study group was group homes. While nearly half (46%) of the study group clients were so placed initially, only about 12% of the study group was living in group homes at the time of the interviews. Foster homes initially received about 10% of the study group while over a quarter (26%) were living in foster homes when interviewed. The proportion of clients placed in natural/adoptive home placements did not vary with about 20% both initially placed in such settings and 21% in such settings at the time of the interview. Semi-independent living settings received about 19% of the study group upon release as compared to about a quarter (26%) who were living in such settings when interviewed. Finally, while only 4% of the study group were initially placed in independent living situations, about 16% were living independently at the time of the interview.

### 7.2.2 Day Placements

Information was collected on the initial and current day placements of the released study group. The most common initial day placement for well over half the group (60%) was to either competitive employment or a sheltered workshop. Another 18% went to a day activity center while 10% were placed in a school program. Five clients (10%) were not initially placed in any day program.

At the time of the interviews however, nearly half the study group (46%) reportedly had changed day placements at least once. Over half (54%) were then working in competitive employment or a sheltered workshop while another quarter were in a day activity center. About 16% were involved in a school program.* For 20% of the study group, no day placement was reported. The most frequently given reason for the lack of a day program was that there were no appropriate programs or jobs in the community or that everyone was having difficulty obtaining employment. Another frequently stated reason was that the study group number was dropped from a program because the placement was inappropriate.

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*Multiple placements were possible so that the percentages given exceed 100%.

## 7.3 Institutional Follow-Up and Study Group Clients

Family respondents were asked if there had been follow-up contact from the institution since the study group member's release. Less than a third (30%) of the respondents reported an institutional follow-up contact. The most common method of contact was by visit to the client's residence. Other methods, much less frequently reported, were by telephone, or contact with someone responsible for the study group member. The most commonly reported frequency of contact for those receiving follow-up was on a monthly basis.

Respondents were also asked about their satisfaction with the follow-up they received. Almost two-thirds were satisfied with the amount of follow-up received while nearly a quarter (23%) reported being dissatisfied with the follow-up from Polk. About 15% said they were neither satisfied nor dissatisfied.

## 7.4 Case Managers and Study Group Members

Family respondents were asked if there was someone who served as a case manager for the released client, i.e. a person responsible for the client's well-being and for the delivery of on-going support services. Virtually all (94%) of the respondents reported that there was a case-manager for the study group members. Respondents also reported that during the first six month period after the client's release, about half these case managers were a staff member from a community agency, and over a quarter (30%) were either the client's parent or housemanager. About 18% were staff members from the institution. During the most recent six month period (prior to the interview) only half the respondents reported a case manager for the study group members. A little over half of these case managers were staff persons from community agencies and over a third were parents or housemanagers.

Respondents also reported that released clients were in contact with their case managers most frequently on a daily basis during both time periods. However, during the most recent six months, about a quarter of the study group were in contact with their case managers or a monthly basis.

## 7.5 Services and Training

### 7.5.1 Services and Training Needs

Family respondents were asked about the support services and training needs of the released study group.* The services cited most often as needed but not received by the released study group from Polk State School were speech therapy, social and/or psychological counseling and camp facilities. The types of training most often cited as needed but not received by the study group were in the areas of vocational training, use of numbers and time, reading and writing, use of social and community agencies and dealing with emergencies.

The support services for the families and housemanagers of the clients most frequently felt to be needed but not received were relief from responsibility (cited by approximately one-quarter of the respondents) and the use of parent or professional associations.

### 7.5.2 Service and Training Use

Family respondents were asked about the client's use of various services and about the client's training in various skill areas. The study group reportedly used an average of 5 support services since their release, while they reportedly received training in an average of 9 different skilll areas.

Family respondents were also asked about the providers of services and training received by Polk's released study group. Of the services used by the study group, respondents reported that almost half (45%) were received from a community agency, while one-fifth (20%) were received from the community residence. The clients day programs reportedly provided 11% of the services, while Polk provided 7% of the used services. Other sources in the community provided 16% of the services recieved by the clients.

Of the training received by Polk's released study group, over half (54%) was reportedly provided by the community residence. A quarter (25%) of the training was provided by community agencies while about one-fifth (21%) was provided by the client's day programs. Respondents reported the less than 1% of the training received by the study group was provided by the institution or other community sources.

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*See glossary for a list of the support services and training areas on which information was collected.

### 7.6 Problems

Family respondents were asked a series of questions about the types and degree of severity of various problems which the released study group may have experienced since release. The most commonly cited problem for the study group was medical problems (for nearly half the group). Other problem areas cited were behavior problems, family relationships, and personal grooming habits.

Study group members were asked which problems they considered to be the most difficult since leaving the institution. The most frequently cited problem was loneliness. Other problems mentioned were finding a job, developing self confidence and budgeting money.

As stated earlier, five study group members had subsequently returned to Polk and were living there at the time of the interviews. Family/Respondents were asked for their reasons for the client's return. The most commonly cited cause for return was behavior problems such as acting out or destructive behavior and difficulty in finding a place to live.

### 7.7 Adjustment

After the interview session, interviewers were asked to record their perceptions of the study group member's adjustment to the community along three dimensions: degree of social isolation, the client's satisfaction or happiness in the community, and the overall adjustment of the client to the community.

Almost three-quarters (71%) of the study group members were perceived by the interviewers as having some social relationships with other persons. Approximately one quarter (27%) of the clients were perceived as being isolated from social relationships. The interviewers were unable to judge the social isolation of 2% of the clients.

Interviewers perceived the vast majority (83%) of the study group as satisfied with their current life. Approximately 12% appeared somewhat dissatisfied. Interviewers were unable to judge the client's satisfaction in 4% of the cases.

The majority of study group members (88%) appeared to be well adjusted to living in the community. Only 12% were perceived to be poorly adjusted, while interviewers were unable to assess the adjustment of 4% of the clients.

# CHAPTER 9.0: SUFFOLK DEVELOPMENTAL CENTER

## 1.0 INTRODUCTION

### 1.1 Overview

The Suffolk Developmental Center, located in New York, is a public residential institution for mentally retarded persons. The Center, which opened about 10 years ago, is operated by the State Department of Mental Hygiene and currently serves approximately 1,825 residents. About 200 of these residents are now living in the community, though they are still considered to be part of Suffolk's population. The Center is striving to place as many residents as possible in their own communities and homes.

The residential population at Suffolk Developmental Center experienced a slight increase in numbers in the past few years. Between 1972 and 1973 there was a 4% increase in the population, from a reported 1,810 clients in 1972 to 1,880 residents in 1973. The 1974 population did not change in numbers from the preceding year. However, between 1974 and 1975, there was a 3% reduction in the population to a reported 1,820 clients.

The age range of Suffolk's residential population has remained stable with approximately 60% of its residents aged 21 and over since 1972. The proportions of males to females has also been consistently around 47% female and 53% male.

One significant change in the composition of Suffolk's residential population in recent years has been the gradual increase of the severely and profoundly retarded populations within the institution. In 1972, about 40% of Suffolk's population was classified as either mildly or moderately retarded. During the following two years, the proportion of mildly or moderately retarded residents dropped to 20% of the institutional population and by 1975, they represented only 10% of the population. Staff at Suffolk attribute this trend to two factors: (1) the increased number of services in the community for mildly and moderately retarded individuals, allowing these residents to be placed out of the institution; and (2) the Center's philosophy that its role is to serve the more severely retarded of the state's population.

The incidence of residents with additional handicapping conditions other than mental retardation has also increased in recent years. Staff report that while in 1972, approximately 60% of its residents had mobility problems or limitations, by 1974 the figure had risen to 70% of its population. Conditions such as blindness and deafness, each affecting about 5% of the population in 1972, were both affecting nearly 10% of the population in 1974. Finally, the proportion of residents with psychiatric difficulties rose from 5% of the residents in 1972 to 15% in 1974. Staff attribute these increases to the fact that the Center now admits only those mentally retarded persons who are severely or profoundly retarded and these people are more likely to have additional handicaps.

Residents are admitted to Suffolk Developmental Center primarily through authorization by parents or guardians. About 75% of the residents were enrolled due to parental or guardianship request in both the past and currently. Staff report that court commitment is generally uncommon in New York State and only 1% of its population is so admitted.

Total expenditure levels at Suffolk Developmental Center increased between 1972 and 1973 by 8% (from $10,376,000 in 1972 to $11,217,000 in 1973). During the following fiscal year, however, expenditures increased by 19% to a reported $13,298,000. However, the 1975 expenditure level was placed at $12,431,000 which represents a 7% decrease from the preceding year.

While staff distributions for the period under study (1972-1974) were not available, information on the increased numbers of social workers was obtained. In 1972, 14 social workers were employed at Suffolk Developmental Center. The following year, there was a 71% increase, to 24 social workers. Staff report that this sharp increase is a reflection of the Center's priorities in providing more individualized services to its residents that was formerly possible.

## 1.2 State Context

### 1.2.1 State's and Institution's Deinstitutionalization Policies

The State Department of Mental Hygiene has established a deinstitutionalization policy consisting of two primary goals: (1) to place as many clients as possible into their own homes and communities; and (2) to help communities develop resources to meet the needs of released clients. Philosophically, this policy evolved in the early 1960s, following the creation of the President's Panel on Mental Retardation. The philosophical commitment was operationalized in 1970-71, when the State Mental Hygiene Law was passed. This law set forth specific directions and guidelines regarding deinstitutionalization. Although Suffolk Developmental Center did not have goals in 1972-1973 for the number of residents to be released, the Center did set such a goal in 1974. Based on a study and a five-year plan developed at the Center by a staff psychologist, a goal of releasing 20 clients in that year was specified.

## 1.3 State Legislation Relating to Deinstitutionalization

### 1.3.1 The Right to Education Law and Its Impacts

The legislation which provides for the education of handicapped children, passed in 1950, is the State Education Law. This law gives every child aged 5-21 the right to an education. Every school district is mandated to provide education to all children in the district area. The district must provide the education itself, or pay for the education of children in special schools. The State Education Law does not clearly specify whether the obligations of school districts include children under 12 who reside full-time in state facilities. Nevertheless, some districts have assumed the financial responsibility if the natural parents of the child reside within their boundaries. The law also applies to children with all types of handicapping conditions. However, if "just cause" exists, the law does provide for suspension of educational services. Children can be suspended temporarily from a school program for assaultive or extreme acting out behavior or for chronic truancy.

Since the passage of this law in 1950, other related legislation has evolved refining the original legislation and focusing on providing comprehensive educational care and increased acknowledgement on the part of the state of its obligation to meet the educational needs of all handicapped citizens. Staff at Suffolk report that while in 1972 and 1973 there was only partial implementation of this law (between 11 and 85% of its residents were served by this law), in 1974, full implementation was achieved.

Staff at Suffolk feel that the Right to Education law may have had impacts in the following areas:

- Small increase in the number of clients served by educational and pre-release programs at the institution;
- Increase in the quality of educational and pre-release programs (due to additional staff allotted for educational purposes);
- Significant increase in the number of clients participating in educational programs in the community;
- Increase in the number of clients receiving other services and participating in other programs in the community;
- Increase in the number of clients released from the institution into community programs; and,
- Decrease in the readmission rates of clients returning from the community to the institution.

### 1.3.2 The Periodic Review Law and Its Impacts

In 1972, the state enacted legislation which mandates that every resident in state institutions be reviewed twice a year. At these reviews, the client's medical condition and living situation are assessed, and a treatment plan is developed. Although the law requires that clients and their parents be present at the reviews, this ruling is not actually adhered to in most cases. During 1972 and 1973, the case review process was in the initial stages of implementation at Suffolk (less than 10% of all clients were reviewed). In 1974, the process was partially implemented (between 11 and 85% of clients were reviewed).

Overall, staff feel that the periodic review legislation has made institutional staff more diligent in looking at individual clients' needs for placement. Staff also felt that the legislation had impacts along the following dimensions:

- Increase in the number of clients served by educational and pre-release programs at the institution;
- Increase in the quality of educational and pre-release programs at the institution (more geared to individual treatment plans);
- Increase in the number of clients released from the institution into community settings; and,
- Decrease in the age of clients placed in the community.

### 1.3.3 State Litigation Relating to Deinstitutionalization and Its Impacts

During 1972-1974, the Suffolk Developmental Center was involved in two suits concerning mentally retarded clients. The first suit was brought by the Center against the Commissioner of Education in a local school district which has refused to admit three children from Suffolk to a local school program. The district feared it would have to pay for the education of these clients, and therefore excluded them. The suit was settled after 14 months of litigation, and the district was required to accept these three children.

The second suit was brought by a local township against a family (foster) care mother who cared for children released from Suffolk in her home. The township, claiming that the family care mother's residence was not zoned properly, ordered that the foster children be returned to the Center. The suit was settled in 1974; the family care mother was fined for a zoning violation, and informal agreements were reached in the township regarding the number and location of family care homes.

The only significant impact of these two suits, according to the Center's Chief of Social Services, was their demoralizing influence on staff. The evidence of community resistance and the extreme length of time required by the litigation tended to dampen the spirits of the staff involved. However, staff feel that by developing a policy of communication rather than confrontation, a more effective response can be achieved. The continuance of community placements and the lack of further legal confrontation support this premise in the Center's opinion.

## 2.0 CLIENT ASSESSMENT PROCEDURES

The procedures used at Suffolk Developmental Center to assess the needs and progress of clients became more thorough during the 1972-1974 period. The basic assessment procedure for clients involves:

- Psychological assessment of client's capabilities;
- Medical review of clients regarding problems which might restrict placement;
- Review of clients' behavioral characteristics that might imply possible adjustment problems;
- Exploration of clients' family situation regarding placement possibilities; and,
- Review of programs which clients need before placement and after release (e.g., vocational and educational training).

Once placement possibilities are considered for a client, his/her family is contacted to obtain their consent to the placement. Two pre-placement evaluative visits to the potential placement are made by the client. Subsequently, the client's adjustment during these visits is assessed to ensure suitability of the placement to the client and vice versa.

During 1972-1974, clients were assessed in the medical, psychological, educational, vocational, and social areas. The percent of clients evaluated and the frequency of these assessments increased during the three-year period as the number of assessment staff increased. For example, the frequency of educational assessments increased from once a year for those clients released in 1972, to twice a year for those released in 1973. Vocational assessments increased from yearly assessments conducted for less than half of the clients released in 1972, to semi-monthly assessments given to 75% of the clients released in 1974.

The following staff regularly participated in assessments of clients released during the three-year period: physicians, psychologists, social workers, nurses, and direct care staff. In addition, vocational rehabilitation counselors, educators, and speech therapists participated in the assessment of clients released in 1973 and 1974.

About one-quarter of the target clients released during the three-year period reviewed and discussed their assessment results with staff. Families, guardians and advocates of clients were also invited to participate in client assessments. The rate of participation of these people increased from virtually none of those clients released in 1972, to almost half of those released in 1974. Persons and agencies from outside of the institution participated in about 25% of the reviews. These persons included foster parents and representatives from schools and vocational workshops in the community.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction

There were six pre-release programs at Suffolk Developmental Center which were available to clients during the period under study. The One-to-One Social Work Program is an individualized program in which a social worker is assigned to each participant in the program to help develop community skills. Building 28 Quarterway House is a program located on the institution's grounds in which 15 to 20 clients live in the house. The Vocational Workshop is a sheltered workshop where clients receive basic vocational and daily living skills. The Competitive Employment Program is a program in which clients work in competitive jobs in the community during the day, and in the evening receive training in community living skills. The Day Work Program consists of clients doing domestic work in the community. Finally, the Split-Item Program, which terminated in 1972, involved institutional work at the Center. In the following section, each program will be discussed in more detail.

### 3.2 Program Descriptions

#### 3.2.1 One-to-One Social Work Program

All of the 137 target* clients released in 1972-1974 participated in the social work program, in which a social worker is assigned to each client to help her/him work on community living skills. The goals of the program are as follows:

- to assess the strengths and weaknesses of each client in regard to community placement;
- To help clients develop attitudes and behaviors which will be acceptable to foster families, peers, and the community at large; and,
- To train clients in skills related to community living, using a modification approach and community exposure during field trips.

During the three-year period, the social worker's role in this program diminished somewhat as more related backup services (e.g., an expanded workshop program) became available at the Center. On the average, clients work with their social workers in this program about five hours per week.

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*See Section 6.0 for description of the target clients.

Approximately 70% of the target clients released in 1972-1974 received training in behavior management through this program. From 1972-1973, about half of the clients participating in the program also received training in self-help skills and personal hygiene; however, only 5 to 10% of the clients released in 1974 received these latter two types of training.

### 3.2.2 Building 28 Quarterway House

The goal of Building 28 Quarterway House is to teach, support and enhance the abilities of clients in a semi-independent living situation. Approximately 15 to 20 clients live in Building 28, which is located on the grounds of Suffolk Development Center. All the participants have their own rooms, and are allowed to come and go at will. Each client participates in an individualized program aimed at preparing him/her both behaviorally and emotionally for eventual life in the community. All of the clients in this program work in competitive employment or workshops during the day. During the evening, there are semi-structured recreational activities available to clients. Group counseling takes place one evening per week. Clients are referred to this program by staff on their living units, on the basis of a high functioning level and the ability to get along with other people.

Approximately 10% of the target clients released in 1972, 1973, and 1974 participated in this program. During this three-year period, all clients participating in the Building 28 Program received training in the following areas: self-help skills, personal hygiene, housekeeping, behavior management, human sexuality, use of community resources, and money management. Half of the clients released in 1973-1974 also received academic training and training in meal preparation. Occupational therapy, films, group discussions, and counseling are employed as techniques to train clients in this program.

The following types of staff are involved in this program (in order of total amount of staff time spent working with clients, from most to least): social workers, vocational rehabilitation counselors, occupational therapists, recreation therapists, volunteers, and direct care staff.

### 3.2.3 Vocational Workshop

The vocational workshop provides a structured setting in which clients receive basic vocational and daily living skills, utilizing a behavior modification/token economy approach. Clients attend the workshop five days a week from 9:00 a.m. to 2:30 p.m. Clients are referred to the program on the basis of case reviews or team meeting recommendations, or on direct referral from a staff social worker.

This program served approximately one-third of the clients released between 1972 and 1974. Target clients participating in the vocational workshop program received training in the following areas: meal preparation, behavior management, use of community resources, use of public transportation, and money management. A smaller number -- from 25 to 50% -- received training in the areas of self-help personal hygiene, housekeeping, human sexuality, preparation for job applications/interviews, and specific job skills. Vocational rehabilitation counselors, psychologists, and social workers are the three major staff types involved in the program.

### 3.2.4 Competitive Employment Program

The goal of this program, which serves the highest functioning clients at the Center, is to foster the client's community adjustment and independence through financial independence. Clients in this program work in competitive jobs in the community, and also receive training in using community resources and public transportation, money management, preparation for job applications/interviews, and specific job skills.

During a typical day in this program, clients take public transportation to their jobs, work an eight-hour day, eat their meals in the community, and return to the institution at night. Once a week in the evening, they meet for group counseling to discuss problems with work.

Referrals to this program are based on the client's ability to work full days, to meet the demands of the employers, and to interact positively with fellow employees. Clients in this program have minimal or no behavior problems -- it is assumed that all of the clients in this program will be eventually discharged to independent living settings.

Approximately 10% of the target clients participated in the competitive employment program before being released from the Suffolk Developmental Center. The major staff involved in this program (in order of total amount of time spent working with clients, from greatest to least) are vocational rehabilitation counselors, social workers, and direct care staff. In addition to working with clients, these staff persons consult with the employers to help them effectively communicate with the clients.

### 3.2.5 Day Work Program

Two target clients participated in the day work program in 1972, where they learned housekeeping skills while doing domestic work in private homes (mostly those of staff persons). Clients can ask to work in this program if the staff physician medically approves this type of work for them. Clients are paid according to rates worked out with the families, usually around 75¢ an hour. The clients are transported to and from work by the families who employ them; some clients work only one hour per day while others work full-time in this program.

### 3.2.6 Split-Item Program

The goal of this program was to simulate a work experience and prepare clients for eventual employment in the community. In this program, the functions of an attendant position were split into five sub-tasks, which were performed by five clients paid at one-fifth rate. The social workers and direct care staff involved in this program met with clients once each week for group discussionson work problems. Four of the released target clients participated in the Split-Item Program in 1972; the program was terminated in 1973 because there was some feeling at Suffolk that this program might b be viewed as a form of peonage or exploitation.

## 3.3 Overall Characteristics of Pre-Release Programs

The Chief of Social Services at the Center cited the positive motivation of staff involved as a major strength of the pre-release programs at the institution. The staff is committed to preparing clients for eventual placement in the community.

The following factors were cited as the major weaknesses of the pre-release programs:

- Lack of sufficient staff to operate quality programs;
- Lack of general competencies -- staff lack specific skills in behavior modification and other techniques;
- Lack of community involvement and support; and,
- Lack of funding.

More staff have been requested for pre-release programs (staff increased in 1974), and a commitment to make the pre-release programs a high priority at the institution has been sought.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

The procedural steps which typically take place prior to a client's release are tied in with the periodic client assessment procedures used at the institution. During the case reviews, the "placement potential" of clients is assessed. Once an appropriate training program is designed to help prepare the client for placement, the client's family is contacted to obtain consent. After the client completes her/his necessary training program and an appropriate placement is found, the client makes trial visits to the placement, generally at least two full weekends. If the client is a child, initial contact is made with the local school district to discuss educational planning. This contact takes place before any placement plans are finalized.

Of the clients released into the community since 1972, the vast majority (about 95%) were released primarily because of institutional initiative, i.e., the institution felt the client was ready for community placement. Few were released as a result of family initiative. The release process is the same for both family-initiated and institution-initiated releases.

The circumstances of initial placement at the institution have no effect on the deinstitutionalization options of clients (e.g., the range of placement options, placement procedures, or responsibilities retained by the institution). The only exception to this policy is in the case of court-committed clients who need the court's signed approval for deinstitutionalization and treatment plans.

### 4.2 Factors Affecting Release

The three most important criteria used at Suffolk Developmental Center to determine whether a client is ready to be placed in the community are: functional level of the client; availability of residential placement in the community; and, availability of day program alternatives in the community. In addition, the consent of the client's parent or nearest relative is a major factor considered in the placement process.

The Chief of Social Services at Suffolk cited the following characteristics of clients who are perceived to be easy to place in the community:

- Inoffensive personal and social behavior (i.e., having a pleasant disposition); and,
- Concurrence of the client's parent or responsible relative regarding placement.

The following three characteristics were cited as relevant to causing difficulty in community placement:

- Anti-social behavior and unusual appearance;
- Lack of concurrence of the client's parent or relative regarding placement; and,
- Presence of medical problems that require special care and supervision.

According to the Chief of Social Services, clients who are typically placed in natural homes are moderately or mildly retarded. Generally, these clients do not have medical problems which require round-the-clock supervision. They are usually involved in some type of day placement, such as a workshop or school program.

There is somewhat more latitude in the types of clients placed in foster homes. For example, foster homes are generally more willing to accept clients of varying levels of retardation. However, like natural homes, foster homes generally did not accept clients with medical problems, physical handicaps or anti-social behavior.

The characteristics of clients placed in group homes are difficult to generalize, since each group home tends to specify its own target group according to age range, sex, geographic area, etc. One the whole, however, group homes tend to focus on clients who function at a fairly high level.

Clients placed in semi-independent living settings generally have a job or regularly attend a day program; they also possess sufficient skills to function "almost on their own." Clients placed in independent settings must possess more than the skills necessary to function independently, according to the Chief of Social Services at Suffolk. The critical variable is the client's emotional independence from the institution. "If a client is still emotionally dependent on the institution as a way of life, then s/he will have great difficulty in adjusting to living in an independent setting."

### 4.3 Client Status Upon Release

All of the 137 target clients released in 1972, 1973, and 1974 were released from Suffolk on an extended visit basis. That is, they were released on a trial visit for an extended period of time, yet remained on the rolls of the institution. The extended visit status can be retained indefinitely by released clients.

None of the client's legal powers (to marry, vote, enter an employment contract, secure legal services, leave the facility, refuse medical or other services) are affected when the client resides at the institution or after s/he is placed in the community.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

The follow-up procedures used by Suffolk Developmental Center to keep track of former clients' progress in the community include monthly mandatory visits by social workers with clients and their foster care parents. Emergency visits are also made as needed, and contact by teachers from the institution with the client's school or workshop is maintained. Also included are letters and telephone calls to the client from the institution, visits by institutional staff to the client's home and work setting, and visits by the client to the institution. Staff report that all of the target clients are followed-up at least once each month by the Suffolk staff.

### 5.2 Support Services Provided to Clients

#### 5.2.1 Agencies with Continuing Responsibility for Clients' Welfare

When a client is released on extended visit into the community, the Center, the public schools (for all children under 21 years of age), and the private agencies in the community have primary continuing responsibility for her/his well-being. This includes the provision of continuing evaluative and follow-up services, and the securing of further changes in placement, if necessary. Once a client is formally discharged into the community, the County Department of Social Services or private agencies specializing in mental retardation services have the primary responsibility for ensuring the client's well-being. According to staff, recent legislation requires that before a client is discharged from the institution, a comprehensive service plan must be worked out for her/him by the institution and appropriate service agencies in the community. Clients on extended visit status are considered to remain on the rolls of the institution, and are not covered by this legislation.

After a client has been placed in the community, s/he maintains the right to return voluntarily to the institution without regard to any waiting lists or waiting periods. Suffolk has the legal power to return the client to the institution involuntarily, but a court order is necessary to do this.

### 5.2.2 Types of Support Services Provided to Clients

The following types of support services were available to all released clients, either at the institution or in the community:

- Social services (monthly visits by a social worker with the client and her/his foster family; contact with the natural family as needed; contact with community resources used by the client);
- Medical care (complete medical follow-up; twice yearly check-up treatment as needed);
- Educational programs (a 5-1/2 hour daily educational program in the public schools);
- Vocational training (vocational and life skills training in a workshop setting); and,
- Competitive employment (daily work in a competitive employment situation).

All of the target clients released from 1972-1974 received social services and medical care. Approximately half participated in educational programs in 1973 and 1974 (less than 15% participated in such programs in 1972). Across all three years, an average of approximately one-third received vocational training, and a relatively small number of those released participated in competitive employment situations. Follow-up social services were provided to released target clients monthly and as needed; medical care was provided bi-annually and as needed; educational and vocational programs and competitive employment occurred on a daily basis.

Follow-up social, medical and vocational services are provided to released clients by the institution itself, while community agencies provide additional medical, educational, and vocational follow-up services. The types of institution staff involved in providing support services included (in order from greatest to least amount of time spent): social workers, nurses, educators, physicians, psychologists, speech therapists, and unit directors. Staff involvement remained constant from 1972 to 1974, with the exception of educators, who did not become involved in providing support services until 1973.

All of the support services provided to released clients were felt by the state school to be adequate, except for vocational training services.

Staff at the Center felt that there were not enough vocational training programs available to meet the needs of released target clients.

### 5.3 Support Services Provided to Those Responsible for Released Clients

The foster families of released target clients receive individual counseling, as needed, by social workers from Suffolk Developmental Center. The Center's teachers and social work staff also provide consultation to the schools into which released clients are placed.

### 5.4 Institution's Assessment of Released Client's Adjustment to Community Living

Suffolk Developmental Center has made informal attempts to evaluate how well released clients are adjusting to life in the community. Staff report that they measure community adjustment by twice yearly case reviews of released clients based on reports from institution social workers and the client's family or housemanager. They also obtain assessments from their professional staff and other agencies working with the released client. The client's feelings about his/her placement and day activity are also probed.

The Chief of Social Services at Suffolk estimates that approximately half of the target clients released during the three-year period under study are adjusting either extremely well or very well. The remaining group are considered to be adjusting moderately well or poorly. The types of clients making an excellent adjustment to life in the community are those who:

- Verbalize and demonstrate happiness;
- Utilize their potential to the fullest degree;
- Cultivate harmonious peer and community relationships;
- Receive intensive individual attention in the home;
- Participate in a rewarding and stimulating program; and,
- Have a desire to remain in their present placement in the community.

The following factors were cited by the Chief of Social Services as probably reasons for the poor adjustment of some clients:

- Offensive negative behavior causing a lack of community acceptance;
- Underachievement (of children in school programs);
- Problems with interpersonal relationships (peers and family);
- Insufficient personal attention in the residential placement; and,
- Expressed or implied desire to leave the community placement.

## 6.0 RELEASED CLIENT PROFILE

For the purposes of this study, released clients from Suffolk Developmental Center were grouped into two categories: target and non-target clients. Target clients are those clients, aged 6 through 40 years, who were released from Suffolk between 1972 and 1974, who had resided at the institution for at least two years prior to their release, and who were released into a community residential setting other than a nursing home or other residential facility serving 100 or more clients. Non-target clients are those clients who were released from Suffolk during the period under study, but who did not meet the above criteria for inclusion in the target group. Since the focus of this study is on the target population, more information was gathered on this group than on the non-target group. In the following sections, a description of the entire released population will be presented, followed by a description of the target and non-target groups separately.

From 1972 to 1974, a total of 160 clients were released from Suffolk Developmental Center. In 1972, 77 clients were released, representing 4% of the institutional population; in 1973, 34 clients were released, or almost 2% of the population residing at Suffolk for that year; and, in 1974, another 49 clients were released, or approximately 3% of the institution's population. During 1972 and 1973, the majority of these released clients were women, between the ages of 18 and 40 years. In 1974, the majority of released clients were males in this same age range. Overall, 30% of the released group were children and/or youth between the ages of 6 and 18 years, 70% were adults, over 19 years of age.

Looking at the released group over the three year period as a whole, the largest group (46% of the entire released population) was moderately retarded. The next largest group was mildly retarded, comprising 27% of the released population. Eighteen percent of the entire group was severely retarded, 4% was profoundly retarded, and 4% of the group had an unclassified or unknown level of retardation.

Very few clients released during this time had secondary handicapping conditions apart from mental retardation. Among those who did, the most frequent secondary handicaps were mobility limitations and seizures.

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* See Glossary for definitions of target and non-target clients.

The circumstances through which the released clients had originally been admitted to Suffolk Developmental Center were generally by self-admission. Court commitment is not customary in New York State, and none of the released clients had been court-committed.

### 6.1 Characteristics of Target and Non-Target Clients

As stated earlier, target clients constitute the focal group of this study. Of the 160 released clients, 86% or 137 persons met the criteria for inclusion in the target group. However, Suffolk Developmental Center was unable to gather all the various types of information needed on the target group for this project. It could only collect the requested data on 66 of the target clients who were placed in family (foster care) homes. Therefore, throughout this section, the target group being discussed refers only to those 66 clients; it does not include the remaining 71 target clients who were placed in natural or group homes. These clients will be considered part of the non-target population, thus enlarging that group to 94 clients.

The largest group of these 66 target clients according to level of retardation was moderately retarded (35%); the second largest group was mildly retarded (30%). The released target clients who were severely retarded constituted 23% of the group while profoundly retarded clients accounted for 6% of the target population. Another 6% of the target clients had an unknown level of retardation.

Of the target group, approximately two-thirds were adults (ages 18 to 40 years). Of the children and youth, moderately retarded persons were the largest sub-group (39%). For adults, mildly retarded persons (35%) comprised the largest sub-group. For both age ranges, profoundly retarded clients were the least numerous level of retardation released.

The majority of target clients released in 1972 and 1973 were females, while the majority of those released in 1974 were males. In 1972 and 1973, the most frequent type of original commitment was voluntary self-admission; approximately half of the target clients released in both years were originally self-admitted. In 1974, original commitment was fairly evenly divided between voluntary self-admissions and admissions by authorization of parents or guardians.

For the non-target population (91 clients) over half were moderately retarded (56%). Nearly a quarter were mildly retarded while 15% were severely retarded. Less than 5% were classified as profoundly retarded. The children and youth age group comprised 27% of the total non-target population. For both 1972 and 1973, the majority of the non-target clients released were females, while in 1974, males were in the slight majority.

For all three years under study, released non-target clients were most often originally committed to Suffolk Developmental Center through authorization of parent or guardian.

Few of those released had additional handicapping conditions other than mental retardation. Of those who did, mobility limitations and psychiatric problems were reported as the most common secondary handicaps.

### 6.2 Skills of Target and Non-Target Clients Upon Release

The types of skills learned by clients released from Suffolk did not vary to any degree during the period under study. In all three years, the abilities most frequently possessed by clients included pre-academics, self-help, and personal hygiene skills. Relatively few clients had learned skills in preparation for job applications and interviews, meal preparation, and knowledge of birth control techniques and human sexuality.

### 6.3 Residential and Day Placements of Target and Non-Target Clients

As stated earlier, the target group from Suffolk went exclusively to foster homes. Of the non-target population, nearly two-thirds were placed in natural/adoptive homes. Almost a quarter were placed in foster homes, while approximately 15% were placed in group homes. Suffolk Developmental Center did not release any clients to semi-independent or independent living situations during the period under study. Staff from the Center report that all of the clients placed in foster homes had visited their prospective placements at least once in the six months prior to their release into the community.

The most frequent day placement for released target clients during the period under study was to public school programs. Although only 15% of the target clients released in 1972 went to public school programs, almost half of those released in the following two years were so placed. The second most frequent type of day placement during the three-year period was to workshops. The day placements for non-target clients was not available.

In 1972 and 1973, over half of the target clients had visited their anticipated day placement prior to their release. Nearly three-quarters of those released in 1974 had made prior visits to their day placements.

### 6.4 Readmissions

Of those target clients released in 1972 and 1973, approximately half were subsequently readmitted to the institution. Several of these clients have since been placed in the community again. Readmissions declined considerably for clients released in 1974; only 18% were subsequently returned to the institution and half of these have been placed in the community again. The rate of readmissions of non-target clients was not available.

In the majority of cases, clients readmitted to the institution who had been released during the three-year period were adults. For those target clients released in 1972, over 80% were 18 years of age or older; in 1973 to 1974, approximately three-fourths were over 18 years of age. The readmission rate of female target clients was much higher than that of male target clients. Over three-fourths of the readmitted clients from 1972-1973 releases were female, while all of those readmitted from 1974 releases were female.

The majority of target clients readmitted to Suffolk Developmental Center had spent less than six months in the community before they returned to the Center. All of the target clients who were readmitted had been released from the institution on extended visit status. (Few clients are given discharge status directly upon release. The Center and the community settings into which clients are placed generally prefer to have clients placed on a trial basis with an extended visit status.)

According to the Director of Social Services, the following reasons were cited for readmission of target clients to the Center:

- Poor adjustment by the clients to his/her parents;
- Foster home was assessed as unsuitable by the institution;
- Need for medical care;
- Foster parents moved; and,
- Client expressed the desire to return to the institution.

## 7.0 STUDY GROUP PROFILE

Of the 137 target clients released from Suffolk Developmental Center between 1972 and 1974, 37 or 27% were interviewed during July and August of 1975 and are referred to as the study group (see Glossary). Of these study group clients, 14 had subsequently returned to the institution after their release and were interviewed there. In this section, information gathered from institutional staff, records, the study group member, his/her family, housemanager, social worker, or other contact person from the community who was interviewed about the study group member will be presented. The information is not intended to serve as a validation of the information gathered from the institution about training, services, or follow-up provided to the study group, nor is it intended to be a "follow-up" of the clients. Rather, it provides another view of the deinstitutionalization process. The descriptive information will be presented on the types of clients interviewed from Suffolk Developmental Center as well as the study groups' perceptions of their problems since release. In addition, information will be presented from the families of the released clients on the institutional follow-up, types of services received, and types of problems encountered since release.

### 7.1 Study Group Characteristics

The age range of the study group was from 8 to 32 years, with an average age of 20 years. The vast majority of the group was white (86%). Over one-third of the study group (36%) was mildly retarded, 41% were moderately retarded, 18% were severely retarded, and 5% were profoundly retarded. The most common disabilities, other than retardation reported among the group were speech impediments (38%) and blindness (17%).

majority (96% and 97% respectively) reported that the person with whom the client came into contact most often was the houseparent. Over 90% of the respondents reported that this contact occurred on a daily basis.

## 7.5 Services and Training

### 7.5.1 Service and Training Need

The services cited most often as needed but not received by the released study group were speech therapy and social and/or psychological counselling.* The types of training cited as needed but not received by the study group were most frequently language skills, travel skills (getting around the neighborhood), and use of the telephone.

The support services most frequently mentioned which the family respondents felt they needed but did not receive were support and/or training prior to the client's coming to the residence (cited by almost one-third of the respondents) and periodic relief from responsibilities.

### 7.5.2 Service and Training Use

The study group reportedly used an average of five services since their release, while they received training in an average of eleven skill areas.

Of the services received by clients, close to half (41%) of the services were provided by the institution, while almost a quarter (23%) were provided by community agencies, and 20% provided by the clients' day programs. About 12% of the services were provided by the community residences, and other community sources provided 4% of the services used.

Of the training received by Suffolk's released study group, almost two-thirds (60%) was provided by the community residences. Almost a third (32%) were provided by the clients' day programs, and community agencies provided 4% of the training utilized. The institution provided 3% of the training.

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*See Glossary for lists of the services and training on which information was collected.

## 7.6 Problems

Respondents reported that keeping a job was the most serious problem encountered by the study group members since release. Other problems mentioned by the respondents included family relationships and behavior problems.

Study group members were asked which problems they considered to be the most difficult since leaving the institution. The three problems most frequently cited were loneliness, psychological problems, and budgeting money.

## 7.7 Adjustment

Two-thirds of the study group members were perceived by the interviewer to have social relationships with other persons. One-third of the clients seemed socially isolated in the community.

Over 80% of the study group members appeared to be satisfied with their current life. Approximately 9% of the clients appeared somewhat dissatisfied. The interviewer was unable to assess the client's satisfaction for 9% of the study group.

Almost three-quarters (73%) of the study group members appeared to be well adjusted to living in the community while another 18% seemed to the interviewers to be poorly adjusted to community life. The interviewers were unable to assess the adjustment of 9% of the clients.

# CHAPTER 10.0: SUNLAND AT TALLAHASSEE

## 1.0 INTRODUCTION

### 1.1 Overview

Sunland at Tallahassee is a state residential facility serving primarily severely and profoundly multiply-handicapped persons. The facility is located near the city limits of the state capital on approximately 44 acres of land. Sunland is a multi-story, single building which was a former tuberculosis hospital. Staff describe the programmatic orientation as stressing developmental, habilitative objectives in an individualized prescriptive program format. The institution, according to staff, is in the process of moving towards community care for its residents.

Sunland's current (1975) residential population of 360 clients represents a 15% decrease from the 1974 population of 425 clients. There was an 8% reduction in population from 1972 to 1973 (from 500 to 460 clients) and another 8% reduction from 1973 to 1974 (to 425 clients). Almost two-thirds (60%) of its 1972 population were female, while in 1973 and 1974 about half the population was female. Currently, 43% of the population is female. Between 1972 and 1974, nearly half the residential population at Sunland was under age 18 while in 1975, about 70% of the residents were over age 18. The majority of Sunland's residents were originally admitted to the facility through authorization of parent or guardian. Less than 10% of the 1972 population were court-committed while virtually none of the current population was originally admitted through the court system.

As stated earlier, Sunland serves primarily severely and profoundly retarded clients. Current (1975) levels of retardation indicate that there are no mildly retarded residents and only one moderately retarded resident at the facility. Nearly 60% of the clients are profoundly retarded, 40% severely retarded. In the previous three years, however, as much as 16% of the population was either mildly or moderately retarded. The vast majority of Sunland's residential population has additional handicapping conditions other than mental retardation. Between 1972 and 1974, about 85% of the population had mobility problems and almost two-thirds were epileptic. Staff report that almost 98% of the current population has mobility problems while about three-quarters are epileptic.

The number and type of staff at Sunland did not change substantially between 1972 and 1974. In 1974, there were approximately 500 staff, over 80% of whom were in the attendant or support staff categories. Current (1975) staff have increased by 22% from 1974 levels to a total staff of approximately 625 members. Nearly three-quarters of these staff are in the attendant or support staff categories. Staff listings include four social workers, four medical doctors, and one rehabilitation/vocational counselor. In addition, the total operating costs at Sunland increased by 43% from 1972 to 1975 (from approximately 3.7 million dollars to 5.3 million dollars).

## 1.2 State Context

### 1.2.1 State's and Institution's Deinstitutionalization Policies

The state has developed, through regulations, a statewide policy setting forth specific goals relating to the deinstitutionalization of Sunland clients. State funds have been set aside for this purpose since 1971. Under guidelines for their distribution, a specified number of clients per year are to be placed in community living situations. In 1973, Sunland informally developed its own policy on deinstitutionalization, with a goal of placing 50 clients per year into community programs. Administrative staff at Sunland formulated the Facility Development Team, which set this goal based on its expectations of the number and types of programs which would develop within community settings. In 1973-1974, 50 clients would have represented approximately 12% of the institution's total population. These goals were not fully attained, however.

## 1.3 State Legislation Relating to Deinstitutionalization

Two education laws in the state apply to individuals classified as mentally retarded. The first, passed in 1973, mandated that by 1975, all students classified as "moderately retarded" and above would be served in the public schools. The second law, passed in 1975, mandated that by 1977, all students classified as mentally retarded, at any level of functioning, would be served by the public schools. The one exception allowed in the second law applied to students receiving services through the Department of Health and Rehabilitative Services, which offers institutional programs, counseling, welfare, etc. Students receiving these services are not eligible to attend public schools under this law.

Between the two laws, children with all handicapping conditions, at all levels of functioning, are covered. Public school systems must offer 13 years of education to students anywhere between the ages of 3 and 21 years; county school systems determine which 13-year age range its school will serve. Staff at Sunland report that during 1974, the only year under study which was covered by these acts, the right to education law was in a stage of initial implementation, i.e. less than 10% of the eligible children were served under the law.

According to staff at Sunland, the Right to Education legislation has had the following impacts with regard to its clients:

- Significant increase in the number of clients participating in educational programs in the community;
- Significant increase in the number of clients receiving other services and participating in other programs in the community;
- Significant increase in the number of clients released from the institution into community settings;
- Decrease in the readmission rate of clients released from the institution into the community;
- Significant increase in the number of severely handicapped clients placed in the community;
- Significant increase in the number of clients placed in family or foster homes; and
- Significant increase in the number of clients placed in group homes in the community.

### 1.3.2 The Periodic Review Law and Its Impacts

While the state has not enacted periodic review legislation, there is a statewide policy on the matter. The policy, which came into effect in 1973, mandates that each client must receive an annual assessment and interdisciplinary review. Policy at the institution mandates that such reviews be conducted twice, rather than once, each year. During 1972, staff reported that the institution's policy was not implemented at all. During 1973, it was in the initial stages of implementation, with less than 10% of the clients being reviewed twice yearly. In 1973, the twice-yearly review process was fully implemented with 85-100% of the clients being assessed.

According to Sunland staff, the periodic review policy has had the following impacts on clients at the institution:

- Increase in the number of clients served by educational and pre-release programs at the institution;
- Small increase in the number of clients participating in educational programs in the community;
- Increase in the number of clients receiving other services and participating in other programs in the community;
- Very significant increase in the number of clients released from the institution into the community;
- Significant decrease in the readmission rate of clients released from the institution into the community;
- Very significant increase in the number of severely handicapped clients placed in the community;
- Wider age range of clients placed in the community;
- Significant increase in the number of clients placed in family or foster homes;
- Increase in the number of clients placed in nursing homes or other institutional settings;
- Increase in the number of clients placed in group homes in the community; and
- More involvement of clients' parents.

### 1.4 State Litigation Relating to Deinstitutionalization and Its Impacts

In 1973, the state was involved in individual litigation regarding sterilization of a mentally retarded client. A former resident of another State School and her family brought suit against a community physician and a community judge who permitted the sterilization procedures. The case was decided in favor of the plaintiffs, and is currently in appeal. As perceived by staff at Sunland this litigation has had no impacts on the institution.

## 2.0 CLIENT ASSESSMENT PROCEDURES

According to Sunland staff, from 1972-1974 formal client assessments were conducted annually by habilitation teams which included professionals from several disciplines, as well as direct care staff involved with the individual client. Areas of assessment for all clients included medical, educational, and social assessments; in addition, from one-third to one-half of the clients received orthopedic assessments during the three-year period, and one-fifth of the clients also received a vocational assessment. A second informal educational assessment was completed each year for clients; the results of this assessment were used primarily for on-going programming purposes. In 1974, Sunland began using its own assessment tool, which is modified each year. This consists of a criteria-referenced, behavioral task analysis. It covers developmental skills from birth to age 18.

During all three years, the following staff were, according to institutional personnel, involved in client assessments: physicians, psychologists, direct care staff, educators, and speech and physical therapists. In 1974, several other staff joined the assessment process, including unit directors, nurses, vocational rehabilitation counselors, and volunteers.

Staff report that no clients released in 1972 or 1973 reviewed or discussed their assessment results with staff; however, over one-third of those released in 1974 had such discussions. During the assessment process, clients may request that they be included in certain programs. Such requests are usually made to staff members with whom the client is friendly, or to volunteer advocates. Staff maintain that each client also has an on-going relationship with her/his social worker, to whom s/he can make such requests.

A Resident Council is currently in operation at Sunland. This is a self-governing group of clients, who serve in an advisory capacity to administrative staff of the institution. Some clients, called Resident Advisors, have also been appointed to certain standing committees within the institution. Through these channels, staff feel that clients have input into decisions affecting their placement options.

During 1972-1973, parents and/or guardians of clients were not generally invited to participate in the regular assessments of released clients. Beginning in 1974, when such invitations were extended, around 10% of those families or persons invited actually attend the assessments.

In some cases, individuals from outside agencies were also invited to participate in the regular assessments of released clients. Such individuals include representatives from the State Division of Vocational Rehabilitation, the Easter Seal Society, the State Department of Education, and an activity center sponsored by the local Association for Retarded Citizens.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction

Sunland at Tallahassee has two separate residential pre-release programs for its clients. The Family Living Unit serves children 1-1/2 to 10 years of age. The Community Readiness Program serves clients 14 years and older. Sunland also offers a pre-release school program (the Community Education Program) which places clients in schools in the community during the day.

### 3.2 Program Description

#### 3.2.1 The Family Living Unit

Staff describe the goal of the Family Living Unit to prepare young children for placement in the community. Emphasis is on independent mobility, public school readiness, and development of self-help skills. A little less than half of the clients released in 1972 and 1974 participated in the Family Living Unit before their release from the institution; approximately 10% of those clients released in 1973 had participated. Clients are chosen for admission to the Unit on the basis of priority for community placement. Such priority in turn depends on family interest and an assessment of entry behaviors.

A typical day in the program begins when clients are awakened at 6:00 a.m. They proceed through their individual toileting, dressing, and bathing programs, then eat breakfast family style. After breakfast, clients go to school until lunch time. Lunch may be followed by physical therapy and speech programs. Evening recreation programs are held after supper.

In 1972 and 1974, staff report that approximately 40% of the target clients (see Glossary) enrolled in the Family Living Unit received training self-help, personal hygiene, behavior management, and pre-academic skills, and a somewhat smaller percentage received academic training. In 1973, only 9% of the target clients reportedly received training in the first four areas, and virtually none received academic training. Percentages vary since students remained in the program longer than one year. By the second year, many students had attained basic skills and participated in community education programs. By 1974, different clients entered the Family Living

Unit. Within this program, self-help skills are taught on an individual basis, using standard task analyses. The Azarin toilet training method is used to accomplish toilet training in a short-term period. Behavior management programs are individually determined by the client's habilitation team, and administered on a one-to-one basis. Pre-academic and academic skills are taught in small groups by the institution's Education Department.

Direct care staff and the Unit Director reportedly spent the greatest amount of time working with clients in the Family Living Unit. Physical and speech therapists, teachers and social workers also contributed a significant amount of time. Other staff who were occasionally involved include physicians and nurses.

### 3.2.2 The Community Readiness Program

Staff describe the goals of the Community Readiness Program, which began in 1973, as teaching basic home management skills, functional academics, and the use of community resources in order to prepare clients for life in the community. Approximately one-third of the target clients released in 1973 participated in this program; half this amount participated in 1974. Clients are chosen to participate in the program on the basis of an assessment of each client's behaviors.

Clients participate in the Community Readiness Program for three to four hours daily. Staff report that in 1973, approximately one-fourth of the target clients received training in housekeeping, meal preparation, behavior management, sex education, academic skills, use of community resources, and money management. In 1974, an estimated 13% of the target clients received training in those areas. All training in the program is based on standard task analyses, criterion-referenced as to the length of time the client needs to complete a particular task. Housekeeping skills are taught individually, based on the client's beginning skills when entering the program. Meal preparation is taught in groups of two or three, with one staff member in attendance. Clients shop for food in the community, and progress is measured according to the amount of time required to shop, prepare and eat an entire meal. Behavior management training in the program is individually prescribed by the client's habilitative team, and administered on a one-to-one basis. Use of community resources is taught both by institution staff and staff at the local Recreation Department. Emphasis is on recreational activities and visits to churches and shops. Money management is taught on an individual basis, with clients learning how to budget and spend their own money.

Teachers and physical therapists spend the most time in the Community Readiness Program. Other staff involved include speech therapists, social workers, and Unit Directors.

### 3.2.3 The Community Education Program

Staff at Sunland reported that the goals for the Community Education Program remained constant from 1972-1974. They are to allow children to participate in public school, to interact with more normal children, and thereby to demonstrate that physically handicapped retarded children can participate in and benefit from public education services. Approximately one-third of the clients released in 1972 and 1974 participated in the Community Education Program; one-fifth of those released in 1973 participated in the program. Clients are chosen for participation upon a screening of school systems and location of an appropriate educational placement. Assessment of entry behaviors is also a determining factor in client selection for this program.

In 1972 and 1974, approximately one-third of the target clients received training in such areas as personal hygiene, behavior management, pre-academic skills, academic skills, and use of community resources such as post offices, banks and shops. In 1973, approximately 18% of those released had received similar training. Students involved in this training attend several different schools, all of whose teaching methods vary. Staff report that some students are in self-contained classrooms, others learn in resource rooms for part of the day, and are integrated with regular students for the remainder. Some clients are in special schools for deaf or blind students.

Teachers and physical therapists spend large amounts of time working with students and community staff in the Community Education Program. Other staff members involved in this program include speech therapists, direct care staff and the Unit Directors.

### 3.3 Sequence of Programs

Sunland staff report that for younger children involved in the Family Living Unit, the sequence of their progression through the various pre-release programs offered begins with their admission to the program. When they have completed the Family Living Unit, they enter the Community Education Program, and from there progress to community placement.

Clients entering the Community Readiness Program live together on one unit of the institution. They participate first in the institution's apartment program, located on Sunland grounds. They then move on to Skyview, a home management training program. Community placement is explored for clients when they complete the Skyview segment.

### 3.4 Overall Characteristics of Pre-Release Programs

According to staff, the major strength across all three pre-release programs is that they are individualized, and cover a wide age range of clients. Programs also deal with critical behaviors that seem to make community placement successful for clients.

The major weakness in pre-release programming at Sunland, as described by staff, is that there is insufficient staff to deal with the institution's population. As a result, staff feel that too few clients are served. Moreover, there are not enough resources with which to work on general behavior problems. Finally, staff cited the institutional environment as a weakness in that the programs are not as community based as would be optimal.

To resolve these problems, staff at Sunland have written staff and resource grants, and have received some funding to hire more staff and obtain more materials and equipment. They have also attempted to elicit more community participation in these programs, and to place the programs in more realistic settings. For example, clients in the Community Readiness Program perform housekeeping tasks in a real home. As many segments of each program as possible take place in the community.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

Staff at Sunland described the release process in operation during 1972 and 1973 as being a simple and informal procedure. When the institution social worker received a request from a family for release of a client or when the social worker knew of a particular program opening and had a certain client in mind for placement, the social worker discussed the client's release with the institution's program and medical staff. If those staff members felt that the client was ready for release, and that the prospective placement was appropriate, then the client was released.

Staff described a more formal process in operation since 1974. Under the state's regional system, each client undergoes a diagnosis and evaluation which leads to the prescription of an optimal residential placement for her/him. The client's habilitative team prescribes the duration of the placement. All clients released from Sunland begin the process in Sunland's region. The regional social worker assigned to the client develops the optimal placement. This placement is then reviewed by the habilitative team, which makes the final decision regarding release. If the placement necessitates a move to a different region, the regional social workers cooperate in implementing the placement.

Staff note, however, that the process differs slightly in the case of family-initiated releases. In these instances, the family may determine the site of the community placement by indicating whether or not the client should be placed near her/his home.

The most important criteria, according to staff, used to determine a client's readiness for placement are her/his functional level, the availability of residential placement in the community, and the availability of day program alternatives in the community in which the client is to be placed.

### 4.2 Factors Affecting Release

According to staff at Sunland, the easiest clients to place are children under the age of 10 whose parents are dedicated to providing for them. Clients are also perceived to be easier to place if the receiving public school system has made a commitment to serve them.

Clients seen by staff as being most difficult to place are those between the ages of 10 and 35, who are non-ambulatory and/or have physical handicaps. They may be severely or profoundly retarded, and usually have no self-help skills, making them totally dependent on others for daily care.

### 4.3 Client Status Upon Release

From 1972-1974, the majority of all releases were institution-initiated, although a smaller majority of releases were institution-initiated in 1974 than in other years. In 1972, a slight majority of clients were released on discharge status, while in 1973 and 1974, the majority of clients were released on extended visit status. During 1972, a client released on extended visit status could retain that status for up to one year. In 1973-1974, clients released on extended visit status could retain the status for six months.

Staff report that the legal powers of clients are not affected solely because they reside at the institution, nor are these powers restricted when clients leave the facility to live in the community. Thus clients have full powers to marry, vote, enter into employment contracts, secure legal services, leave the facility, and/or refuse any services offered by the facility. Circumstances of the client's original placement at the facility do not have any effect on her/his options for placement within the community.

Clients released from Sunland do have the right to return voluntarily to the facility without regard for waiting lists or waiting periods. The institution may return a client involuntarily to the facility only through court action.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

The main source of follow-up for released clients is the regional mental retardation office, although Sunland staff report they often follow up clients' progress through occasional informal checks. Informal checks were described by institution staff as usually made by letter or phone to the regional office involved. On the average, regional office staff follow up clients at least once a month. Between 88% and 93% of the clients released in 1972, 1973, and 1974 were followed up by regional office staff.

### 5.2 Support Services Provided to Clients

#### 5.2.1 Agencies With Continuing Responsibility for Clients' Welfare

According to Sunland staff, the Regional Office of the State Division of Retardation has primary continuing responsibility for ensuring the well-being of released clients. This is true whether the client is released on extended visit or discharge status.

#### 5.2.2 Types of Support Services Provided to Clients

In 1972 and 1973, support services were reportedly provided to released clients in the areas of medical care, education, and social services. In 1974, additional services were offered in the areas of vocational training and recreation. Across all three years, social services were provided on a monthly basis, educational programs received annual support, and medical care was provided on an "as needed" basis. The vocational services added in 1974 were provided daily by rehabilitation counselors, and recreational programs were offered monthly.

From 1972-1974, all of the clients released received follow-up medical care, and the large majority received social services. Somewhat less than half of those released in 1972 and 1974 participated in educational programs, although less than one-fifth of the clients released in 1973 participated in such programs. Half of the clients released in 1974 received vocational training and participated in recreational programs.

Across all three years, the main provider of social services for adults was the regional mental retardation office, while the main provider of social services for children was the Children's Home Society. In 1972, Sunland was the primary provider of medical care for released clients. During the following two years, the regional mental retardation office was responsible for the provision of this service, but used institution staff to actually deliver the medical care. Across all three years, support to educational programs was provided primarily by the regional mental retardation office. In 1974, the office also provided vocational training, and monitored recreational programs offered by local agencies. Sunland staff involved in support service provision included social workers, educators, unit directors, and, in 1972 only, physical therapists.

All support services were considered by Sunland staff to be adequately provided, with the exception of recreational programs. These programs, which were provided only in 1974, were felt to be inadequate by institution staff.

### 5.3 Support Services Provided to Those Responsible for Released Clients

During 1973 and 1974, Sunland staff report that they provided training to client "families" to prepare them to work with clients. Natural and foster families received training in behavior management and teaching self-help skills, and group home parents received training in behavior modification techniques.

From 1972-1974, the institution reported also providing training to the employers and teachers of released clients in order to facilitate placement and ensure long-term success of released clients. Teachers were trained in behavior modification techniques. In addition, institution staff helped to phase released clients into the public schools, and spent considerable amounts of time in the classroom for the first month or two of placement. During 1973 and 1974, employers of released clients were taught basic behavior modification techniques by institution staff.

### 5.4 Institution's Assessment of Released Clients' Adjustment to Community Living

Sunland at Tallahassee staff reported that they do not officially attempt to assess how well released clients are adjusting to community living. However, the institution sends updated diagnostic and evaluative materials, as well as prescriptive programs, to the regional mental retardation office, and that office then handles all aspects of the clients' life in the community.

Staff report, however, that they do make informal assessments on released clients' adjustment. The main criteria by which these assessments are formed are the lack of conflict in the client's living situation and the day placement or training program. Clients considered by staff to be making excellent adjustments to the community are those with minimal retardation and physical problems. Clients making a poor adjustment to community living are those who have severe behavior problems and those with ongoing medical difficulties.

Institution staff estimate that about two-thirds of the released target clients are making a very good adjustment to community living, about a quarter are adjusting moderately well, while about 10% are adjusting poorly.

## 6.0 RELEASED CLIENT PROFILE

As stated in Section 1.0, clients released between 1972 and 1974 were grouped into two categories: target and non-target clients (see Glossary). In this section, information is presented first on the overall released population from Sunland during this time period, and secondly, on released target and non-target clients separately. Since the focus of the study was on target clients, more information was collected for this group than on non-target released clients.

Between January 1, 1972 and December 31, 1974, Sunland at Tallahassee released 103 residents. In 1972, 24 clients were released, representing 5% of the institution's population. In 1973, the largest group of 41 clients was released, or 9% of the population, while in 1974, another 38 clients were released or 9% of the residential population for that year. The majority of released clients were female in 1973 and 1974 while in 1972, a little less than half were female. About 40% of those released were children and youth (i.e., aged 18 and under).

There was a wide variation in the percentage of released clients by levels of retardation. About 22% were mildly retarded, half were moderately retarded, about a quarter were severely retarded, and the remaining 2% were profoundly retarded.*

The settings in which the released population were placed were varied. About a third were placed in either natural/adoptive homes (31%) or in group homes (39%). Another 15% were placed in nursing homes, and 13% went to foster homes. Finally, 3% were placed in other unspecified settings.

### 6.1 Characteristics of Target and Non-Target Clients

Of the 103 released clients from Sunland, 66 or 64% were considered target clients for this study. Releases of target clients were lowest in 1972, when 16 target clients were released. The largest number of target clients was released in 1973 when 29 were deinstitutionalized. Finally,

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*Many of the released group had additional handicapping conditions other than mental retardation. The most prevalent additional handicap was mobility limitations. Psychiatric problems, and epilepsy were other types of handicaps frequently noted by Sunland staff.

21 target clients were released in 1974. A small majority of these clients were children and youth between the ages of 6 and 18. In 1972 and 1974, the majority of those released were male while in 1973, the majority were female.

The remaining 37 released clients, or 36% of the overall released group were considered non-target releases. In 1972, there were eight non-target releases. In 1973 there were 12 non-target releases and in 1974, 17 non-target releases. Three-quarters of the releases in 1972 and two-thirds of the releases in 1973 were female. In 1974, a little over half the non-target releases were female. The vast majority (84%) were over age 19.

For both target and non-target clients, over half the releases in each group were moderately retarded. Over a quarter of the target releases were mildly retarded, 21% were severely retarded and 1% was profoundly retarded. Non-target releases included 14% mildly retarded, one-third severely retarded and 3% profoundly retarded.

Additional handicapping conditions for the target populations were most frequently mobility limitations, psychiatric problems, and blindness or deafness. The most common additional handicaps of the non-target group were psychiatric problems, mobility limitations and epilepsy.

About three-quarters of the non-target released clients were originally committed to Sunland through the court system. For the target group, the majority were originally committed through authorization of parent or guardian.

### 6.2 Skills of Target and Non-Target Clients Upon Release

Information on the skills of released clients from Sunland at Tallahasses was collected on target releases only. The most common areas in which clients received training were self-help skills, personal hygiene, behavior management, and pre-academic skills. Less than half the released target clients received training in academic skills, using public agencies, and sex education.

## 6.3 Residential and Day Placements of Target and Non-Target Clients

As defined earlier, target clients were released to community placements other than nursing homes or other facilities serving 100 or more clients. Of the 66 target clients released from Sunland during the period under study, 47% were placed in natural or adoptive homes. About 45% were placed in group homes while the remaining 7% went to foster homes.

Non-target clients included those clients released to nursing homes or other facilities and clients not within the specified age range. For this group, group homes were the most frequent placement (39% of the group). Natural/adoptive homes received 30% of the non-target releases while 15% were placed in nursing homes. Another 13% went to foster homes and the remaining 3% were placed in other institutional facilities.

The types of day placements in which target clients were placed upon release were unknown to Sunland staff for a quarter of those target releases in 1972 and for over half of the target releases in 1973 and 1974. Many of these unknown placements were arranged by the clients' families. Placements of which Sunland staff did have knowledge for target clients were predominantly to public school programs or private school programs. Other types of placements utilized were to competitive employment or sheltered workshop. The day placements of non-target clients was not obtained.

## 6.4 Readmissions

Readmissions of target clients were most frequent for those clients released in 1972, of which four clients were readmitted (6% of the target releases). Of the 1973 and 1974 releases, two were subsequently readmitted to Sunland. Of these six readmitted clients, two were males and four were females. All the readmitted clients from the 1972 and 1974 releases were children and youth while the one readmitted target client released in 1973 was an adult. All readmitted target clients had been in the community for less than six months at the time of their return. Group homes were the most common setting in which readmitted clients were living before return. One client was readmitted from a foster home and one from a natural home. All the clients from 1972 and 1973 releases were on extended visit status while the readmitted client from the 1974 releases was in discharge status.

The reasons cited by Sunland staff for readmission of target clients were that the group home was closed by the state for being inadequate. One returnee was experiencing medical problems and another returnee's natural home dissolved, thus precipitating return to Sunland.

Information on the return rates of non-target clients was not obtained.

# CHAPTER 11.0: UTAH STATE TRAINING SCHOOL

## 1.0 INTRODUCTION

### 1.1 Overview

The Utah State Training School is the only public facility for mentally retarded persons in this southwestern state. Comprised of approximately 15 residential buildings, it provides services ranging from total nursing care to minimal supervision in apartment-type living situations. The underlying goal, as described by staff at the Training School, is to provide as normal a daily living situation as possible for its residents. A variety of institutional activities are provided such as movies, dances, church and recreational activities in order to broaden the experiences of its clients. According to the staff at the facility, a concerted effort is made to prepare as many clients as possible for community placement. In operationalizing this philosophy, extensive support services have become more readily available in recent years. These services are geared at improving the quality of institutional care and meeting the training needs of its mentally retarded population. Staff cite examples of the types of services provided such as speech and physical therapy, vocational and pre-vocational training, and improved medical and dental services. The State School is also working towards accreditation for funds from Title 19 of the Social Security Act (Medicaid) which will provide further aid for existing programs and services.

The current (1975) population at Utah State Training School is approximately 930 residents. Included in this figure are residents in nursing homes and residents who are on extended visit status (see Glossary for definition) and therefore, are still considered to be residents of the school. Approximately 80 of these residents live in one of the 14 group homes located within a 50-mile radius of the State Training School. All of these homes have been opened since 1970 and generally serve a mildly retarded population, some of whom have additional handicaps besides their mental retardation. Staff from Utah State Training School report they are continuously involved in the group homes in the provision of weekly follow-up for its residents.

The actual population in the State School increased by 9% between 1973 and 1974 (from 850 in 1973 to 928 in 1974). There have been only slight increases since that time. The majority of the residents are male (approximately 57%) and a little less than half (439) of the residents are 18 or under.

Information on how deinstitutionalization may have effected the proportions of residents by levels of retardation over the 1972-1974 period under study are not available. Of the 1975 residential population, however, over 50% was classified as profoundly retarded. Over a quarter of the residents were severely retarded. Approximately 10% were mildly retarded while 13% were classified as moderately retarded. Information on additional handicapping conditions of Utah's residential population was not available.

Per capita expenditures at the State Training School increased by 23% between 1972 and 1973 (from approximately 4.6 million dollars to 5.6 million) and again by 24% between 1973 and 1974 (to almost 7 million dollars). An additional 18% increase in expenditures was reported between 1974 and 1975 (to almost 8½ million dollars). Staffing patterns have also shown marked changes in recent years. Between 1973 and 1974, there was an 11% increase (from 717 staff to 793 staff members) in the number of staff employed by the State School with the attendant staff category accounting for over half the total staff in both years. Another major staff category reflecting this expansion was the teacher category (including both certified and non-certified teachers and aides). Whereas in 1973, teachers constituted 7% of the total staff, in 1974 teachers accounted for 20% of the total staff. However, between 1974 and 1975, the staff at Utah State Training School decreased in numbers by 5%. Again, changes in the number of teachers reflect the major variation in staff distribution. This category, in 1975, represented 4% of the total staff. Support staff (non-direct service jobs such as maintenance workers) have increased in recent years, now constituting 14% of the 1975 staff listings as compared to 10% of the staff in 1973 and 1974.

## 1.2 State Context

### 1.2.1 State's and Institution's Deinstitutionalization Policies

While the state has not set forth specific guidelines relating to deinstitutionalization, the institution has developed its own policy in this area. Since the present Superintendent's arrival at the State School in 1967, the philosophy of the school has been to place as many clients as possible in appropriate community settings which can provide comparable or better programs and services which meet the resident's needs. No specific goals have been set for the number of clients to be placed in the community.

## 1.3 State Legislation Relating to Deinstitutionalization

### 1.3.1 The Right to Education Law and Its Impacts

In 1969, state legislation was passed in Utah which provides for the education of all handicapped children between the ages of 5 and 21, regardless of the child's handicapping condition. This free public education may be extended to age 30 if the student is seeking a diploma, the additional cost being covered by revenue from taxes. While all severity levels of handicaps are covered by the legislation, students may be declared exempt by an evaluation team established through the local education agency if the student is judged "a hazard to self or others." Staff report that during the 1972-1974 period under study, this law was in a stage of partial implementation with between 11-85% of its clients being provided an education according to this law. The impacts of this law have not yet been assessed by the staff at the Training School.

### 1.3.2 The Periodic Review Law and Its Impacts

While the state has not enacted periodic review legislation, the State Training School requires that every resident be reviewed at least annually. Staff report that this policy was established in 1967, and was fully implemented in 1972-1974, with 85% to 100% of the institution's clients reviewed each year. Staff at the State Training School feel that the periodic review has been effective in determining which residents are ready for different programs but has not affected nor been used to determine the numbers of residents within particular programs.

## 1.4 State Litigation Relating to Deinstitutionalizaiton and Its Impacts

During the years 1972, 1973, and 1974, the state was not involved in any class action or individual litigation concerned with individuals classified as mentally retarded.

## 2.0 CLIENT ASSESSMENT PROCEDURES

Staff report that regular assessment of clients at Utah State Training School were conducted throughout the three years under study. Psychological assessments occurred once every two years while medical, educational, and vocational assessments took place annually. The primary staff included in these reviews were the Superintendent, unit directors, social workers and institutional educators. Representatives from the State Division of Family Services and from the Division of Vocational Rehabilitation were generally invited to participate in regular assessments as were the families or guardians of the clients being assessed. In addition, about half of the target clients released during this period reviewed and discussed their assessment results with staff. This number, staff report, represents all the target clients who were capable of such discussions.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction

Clients released in 1972-1974 participated in three types of pre-release programs: the Here and There Program, which places clients in community public schools during the day; the Work Station Program, which allows adult clients to refine their work skills in a setting on the institution grounds, and the Here and There Work Program, in which clients are placed in jobs in the community while still residing at the institution. Utah State Training School also operates a separate residential program, consisting of a small apartment, which prepares clients for community living; however, none of the target clients released during 1972-1974 participated in this program. The following discussion describes the three pre-release programs available to target clients during the period under study.

### 3.2 Program Descriptions

#### 3.2.1 The Here and There School Program

The Here and There School Program places children from Utah State Training School into local community schools during the day. The goal of the program,as described by staff, is to provide children with as near normal school experiences as possible, and to furnish appropriate educational instruction. A child is selected for the program by recommendations from the educational staff at the institution and the unit director responsible for that student. The recommendation for enrollment in the school program is made to the Assistant Superintendent of Program and Professional Services who then surveys the local school program to find an appropriate placement for the student. Approximately 2% of the target clients released in 1972 and 1973 participated in the Here and There School Program; no target clients released in 1974 participated in this program.

The program operates in a self-contained classroom in a local public school. While the school is part of the local education system, the building houses only special education classes. Students in the program are not integrated with students in regular classes at any time. The students in the class are taught in a group by one teacher and one aide. Staff at the Training School report that all students participating in the Here and There Program received training in personal hygiene and behavior management. In addition, training in pre-academic skills such as identification of shapes, colors and numbers was received.

A typical day in the Here and There Program begins when the students arrive by bus from the institution. In the classroom children participate in various activities such as coloring, beginning reading, pre-academics, music, and physical education. A speech therapist also works individually with each student for one hour a week. Field trips downtown are part of program activities, and children also participate in the Special Olympics. The school day runs from 9:30 a.m. to 3:00 p.m.

### 3.2.2 The Work Station Program

The Work Station Program is located on the grounds of the institution and is available to those adults referred by the unit staff to the State Division of Vocational Rehabilitation. This division administers vocational tests and on the basis of the test results, places clients in work stations. Staff describe the overall goals of the program as being to help clients develop specific job skills, to provide clients with as near normal life experiences as possible, and to increase the clients' independence so that they can live successfully in community settings. The more immediate objective of the Program is to allow clients the opportunity to refine their work skills before moving to the Here-and-There Work Placement Program.

Approximately 5% of the target clients released in 1972 and 1973 participated in the Work Station Program; this percentage tripled for target clients released in 1974.

Clients involved in the Work Station Program receive advice and assistance from program staff on such topics as appropriate dress and personal hygiene. They are checked for dress and cleanliness by the staff who communicate regularly with the client's living unit staff. Supervisors receive assistance from the institution's Psychology Department on methods to encourage clients to improve their social behavior. When clients behave inappropriately, they may lose recreation time or the social part of their work break. Academic training in this program is specifically related to the clients' jobs. This training, which is administered on an individual basis by supervisors, includes such tasks as measuring, counting, and reading directions. Supervisors also advise clients on the appropriate use of community resources such as banks, shops and post offices, and cooperate with vocational rehabilitation counselors in preparing clients for job applications and interviews. Clients have their own money, and receive training on an individual basis in regard to making change and budgeting.

When clients arrive at their work stations, they punch in on a time clock. Each client is then assigned to a specific job by a training aid. Jobs last for two hours or for four hours with a break. During the break, the client can visit the canteen or the kitchen. They may be given canteen slips as rewards for good work habits. When clients return from their lunch hour, they are assigned to different tasks. Tasks are rotated on a particular job so that clients can learn many aspects of that job; when the clients become proficient in one task, training aides try to help them increase their proficiency in other tasks. Clients are rated daily on their skills, and are paid once each week, either in money or tokens. Special rewards for good work are given in cash.

Staff who spend time with participants in the Work Station Program include job training aides, vocational instructors, direct care staff, and vocational rehabilitation counselors.

### 3.2.3 The Here-and-There Work Placement Program

In the Here and There Work Placement Program, clients live on the institution grounds and work during the day in community settings. The utlimate goals for the Work Placement Program, as described by Utah staff, are similar to those for the other two pre-release programs: to provide clients with as near-normal life experiences as possible, to teach job skills, and it increase clients' independence so that they can live successfully in community settings.

Clients in the Here and There Work Placement Program either learn or refine specific job skills in on-the-job training or on an individual basis with the assistance of their supervisors. Staff report that vocational rehabilitation counselors, vocational instructors, unit directors and direct care staff have the greatest input to clients involved in the program. Participants in the program are employed by community industries. Salaries and working hours vary according to the job involved.

Of those target clients released in 1972, 12% had participated in the Here and There Work Placement Program. None of the clients released in 1973 had participated in the program, and 3% of those target clients released in 1974 had been involved. While clients are in the Here and There Work Station Program, unit staffing meetings are held to determine the clients' progress in the program; these staff meetings include Vocational Rehabilitation staff. Decisions to move clients from the Work Station to the Here and There Work Placement Program are made at such meetings.

### 3.3 Sequence of Pre-Release Programs

Staff report that typically a client first attends a school program and then is evaluated by the State Division of Vocational Rehabilitation. If s/he becomes a Division client, s/he is assigned to on-the-job training on the grounds of the institution (the Work Station Program). The client may then be certified by Vocational Rehabilitation, and participate in the Here and There Work Program. If a good adjustment is made to working in the community, the client may then be recommended for community residential placement.

### 3.4 Overall Characteristics of Pre-Release Programs

Utah State Training School administrators listed three major strengths of the institution's pre-release programs. These were: (1) highly skilled and qualified staff; (2) good facilities, including training materials and equipment; and (3) excellent community acceptance of released clients. Staff at the State Training School continue to develop these three areas as the improvement of the programs within the institution progresses. For example, staff from the School applied for and received federal grants to provide more funds for their programs as well as going to the state legislature to stress the importance of adequate funding for the institution. The state legislature responded favorably as evidenced by a 360% increase in the Training School's budget in the last seven years.

Staff at the School have also solicited community support to generate acceptance for the increased placement of its residents into community work and residential settings. Program staff and administrators meet with service clubs in the state and with every city council member as well as with county commissioners. Filmstrips have been developed on institutional programs, and a strong volunteer services department has been established within the institution. During the summer, 100 young people (18-20 years old) are hired to work with staff in providing recreational rehabilitation programs for the institution's residents. The Training School has also encouraged the activities of the Leaders of Tomorrow Program to include participation in the School's life. These high school students spend a day at the School meeting the residents and staff and participate in an orientation session. The Public Information Officer at the Training School arranges for as much publicity as possible, through radio and television stations, as well as the news media. As a result of these efforts, many students have become volunteers at the institution, and in some cases, later enter the field of retardation as a career. Speaking engagements and media presentations by members of the State Training School staff have helped people in the community to become more knowledgeable about and involved with the School's clients.

Staff feel that the major strengths can also be considered to be the major weaknesses of the pre-release programs in that staff would like to see more personnel, better facilities, and more community acceptance and involvement in the programs.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

Release procedures at Utah State Training School were basically the same for all three years under study. A Placement Committee operating within the institution and chaired by the Superintendent, holds primary responsibility for recommending community placement for the results. This committee is composed of programmatic professionals, social service, staff, and medical and psychological staff. Any staff member in the State Training School may make a referral for placement to the Placement Committee. Generally, direct care staff, unit directors, or social workers play a key role in referring clients for placement. In addition, clients themselves can indicate their desire to be considered for community placement to any direct care or Social Service staff. This may lead to a staff member's recommendation that a review be made concerning community placement for the client.

When a client is referred to the Placement Committee, a notice is sent to every discipline area in which the client is involved requesting a report outlining the client's progress and making recommendations for placement. Two weeks are allowed between the referral and the meeting date of the Committee. If the client is able and/or willing to participate, s/he is encouraged to attend the meeting. The client's family is also invited to participate. During the 1972-1974 period, about 10% of the families or guardians of the target clients being assessed actually participated in the assessment procedures. However, Social Service staff report that they always obtained family or guardian feedback on recommendations made regarding the clients.

If the Superintendent, as Chairperson of the Placement Committee, makes an initial approval for the development of community placement plans, Social Service staff at Utah State Training School contact the appropriate community agencies and, in cooperation with the State Division of Family Services, make arrangements for the placement to be effected. If employment is involved, Vocational Rehabilitation staff are also included in this process. Social Service staff then present the comprehensive and detailed placement plans to the Placement Committee for final approval. An immediate review of these plans is made and if it is accepted by the Committee, it is formally approved by the Superintendent and implemented. Modifications can be made in this process if an immediate placement is available to the client upon the initial referral.

### 4.2 Factors Affecting Release

The existence of an appropriate community program is the most important factor in determining when clients are considered for community placement. A client is placed only when, according to staff, an appropriate community residence, school, or work situation and counseling are available simultaneously. The availability of leisure time activities is also considered when a placement is to be effected. According to staff, the type of residential setting into which the client is placed is determined by the individual client's skill levels.

Staff at Utah State Training School describe clients easiest to place as those classified as mildly retarded who have a fairly normal appearance, who are non-aggressive, and who have no physical handicaps. Among clients considered difficult to place are those who are classified as profoundly retarded. They may also be aggressive and/or abusive, or have abnormal appearances. Clients with multiple handicaps or sexual deviations are also difficult to place in many instances.

### 4.3 Client Status Upon Release

Across all three years, the large majority of clients were released as a result of institution, rather than family, initiative. In 1972 and 1973, most clients were released on extended visit status, although in 1974, approximately one-third were released on discharge status. Clients released on extended visit status are able to retain this status indefinitely.

According to staff, clients' legal powers are not restricted merely because they reside at Utah State Training School. Thus, they retain their rights to marry, vote, enter employment contracts, secure legal services, leave the facility, and refuse services offered by the facility, both while they reside there and after their release.

Clients' deinstitutionalization options are not affected by their original admission status. The state gives the Superintendent the authority to place clients into community settings on a discretionary basis. Clients have the right to return voluntarily to the State School without regard to any waiting lists or waiting periods. For clients on extended visit status only, the institution does have the legal power to return the individual against his/her wishes.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

During 1972, 1973, and most of 1974, the institution provided all follow-up for its released clients, through letters, telephone calls, regular staff visits to the clients' homes, and regular client visits to the institution. In the latter part of 1974, this role was assumed by local branches of the State Division of Family Services. This change was consistent with a philosophy of decentralizing services so that clients could be assisted near their own residential settings. However, the School retains all follow-up responsibilities for clients released to group homes under the School's auspices. Social service staff at Utah State remain aware of other released clients' progress through contacts with the social service staff of the State Division of Family Services. Across all three years, when employment was involved, the Division of Vocational Rehabilitation followed clients along in their work settings.

Staff report that during 1972 and 1973, all released target clients were followed up on an as-needed basis, but at least once a year. During 1974, group home clients were followed up once a week, according to staff.

### 5.2 Support Services Provided to Clients

#### 5.2.1 Agencies with Continuing Responsibility for Client's Welfare

The institution retains primary legal responsibility for clients released on extended visit status. Once a client is discharged from the institution's roles, however, the State Division of Family Services assumes continuing responsibility.

#### 5.2.2 Types of Support Services Provided to Clients

The percentage of released target clients receiving various types of support services remained constant for 1972-1974 according to staff. All individuals in natural homes, group homes, and independent living situations, received social services. A little less than half received vocational training, approximately 20% participated in recreational programs, and relatively few participated in educational programs.

Across all three years, medical care was provided to clients through private physicians in the community on an as-needed basis. During 1972 and 1973, social services, including group therapy, individual counseling, consultation and homemaker services, were provided monthly by the institution. During 1974, the State Division of Family Services assumed this role for clients living in the community. Across all three years, the institution was the main provider of educational and recreational programs. Educational services were provided on an as-needed basis while recreational programs were available monthly. The State Division of Vocational Rehabilitation provided vocational training to clients attending community sheltered workshops; the institution provided vocational training to other clients as appropriate.

A variety of staff at the institution were involved in the provision of follow-up support services to clients released from 1972-1974. In order of the amount of time spent providing such services, they included: social workers, vocational rehabilitation counselors, physicians, educators, psychologists, volunteers, the Superintendent of Utah State Training School, unit directors, nurses, physical therapists, speech therapists and occupational therapists.

Staff considered medical care provided to released clients to be adequate. Other services, including social services, vocational training and educational and recreational programs, were judged to be inadequate. (This evaluation was based on the administration's philosophy that clients always need more and better services.)

### 5.3 Support Services Provided to Those Responsible for Released Clients

From 1972-1974, the Utah State Training School reportedly provided no formal services or training to either the families or the employers/ teachers of released clients, although some informal attempts were made toward orientation of released clients' families.

### 5.4 Institution's Assessment of Released Clients' Adjustment to Community Living

The State School reported that they attempted to assess the adjustment of clients released to group homes only. Clients are informally assessed during weekly visits by Utah staff to group homes, during which individual counseling is provided. According to staff, the criteria used to determine whether clients are adjusting well to their community placement include the successful employment or school placement of the client, the degree to which the client can live independently with a minimum of supervision in the home, and the degree of acceptance by the community of the client. More subjective criteria used by staff to assess a client's adjustment in the community are the quality of interaction of the client with others and his/her demonstration of socially acceptable behaviors. Staff from Utah State Training School feel that an important aspect to a client's adjustment is the level of involvement and support which the client receives from his/her family or from someone in the community (either professional or lay) to whom the client looks for support. Staff also stress the importance of good grooming habits which facilitate general community acceptance of released clients.

Factors generally contributing to a less than successful community adjustment include aggressive, anti-social behavior, the resistance to limitations or structure imposed by programs or work assignments and lack of support or guidance from the client's family. Staff also noted that the lack of competent community support services for mentally retarded persons is an additional factor for poor adjustment.

On the basis of these criteria, the staff at Utah State Training School estimate that over half of the clients released between 1972-1974 are adjusting extremely well or very well. About a third are adjusting moderately or fairly well, while about 4% are experiencing a poor adjustment.

## 6.0 RELEASED CLIENT PROFILE

As stated in Section 1.0 , released clients between 1972 and 1974 were grouped into two categories: "target" and "non-target" clients (see Glossary for definitions). In this section, information will first be presented on the entire deinstititutionalized population of 1972 through 1974, and secondly, on the target and non-target populations separately. Because the focus of this study was on the target population, more information was gathered on this group than on the non-target group.

Between 1972 and 1974, a total of 178 mentally retarded persons were released from Utah State Training School. In 1972 81 clients were released (about 10% of the institution population), in 1973 54 clients were released (6% of the population), and in 1974 another 43 persons were released (5% of the population). Of the 1972 and 1973 releases, less than half were female while in 1974, the slight majority were female. Nearly one-quarter of those released were children and youth (ages 6 through 18 years) while the remaining three-quarters were 18 years of age.

Approximately half of the total released population was mildly retarded (49% or 88 clients). Moderately retarded clients constituted 20% of the total, while 17% were severely retarded and 14% were profoundly retarded.

For the overall released population, there was a fairly even distribution of residents being placed into a variety of residential settings. The most prevalent residential setting was natural/adoptive homes which received almost 30% of the released group. About 20% were released to independent living situations (only adults) and a similar proportion were released to nursing homes. Group homes received 20% of the total released group, while less than 5% were placed in foster homes and less than 5% in semi-independent living situations.

Information on additional handicapping conditions besides mental retardation was not available on either the target, non-target or total groupings.

## 6.1 Characteristics of Target and Non-Target Clients

The target group of released residents from Utah State Training School numbered 133 residents, or 75% of the total number of released between 1972-1974. In 1972, 59 target clients were released, representing 7% of the entire institutional population. In 1973, another 39 target clients were released, constituting 5% of the total institutional population. Finally, in 1974, 35 target clients were released, representing another 4% of the Utah State Training School population.

The non-target released population numbered 45 residents during the three years under study. Almost half of this group (22 residents) were released in 1972, accounting for close to 3% of the total institutional population in that year. In 1973, 15 non-target clients were released (2% of the total institutional population); while in 1974, only 8 non-target clients were released (less than 1% of the population residing at the Training School in that year).

Approximately 31% of the target group were children and youth (ages 6-18 years) while of the non-target group released during the period under study, only 3% were children and youth. In 1972, less than half of the target clients were female (41%), while in 1973 and 1974, roughly equal numbers of men and women were released in the target group. For the non-target clients, there was a wider variation so that in 1972, about half of the released people in this group were women whereas nearly two-thirds were women in 1974. In 1973, however, only 20% of those released in the non-target category were women.

Mildly retarded clients were the most commonly released persons in both the target (56% of the total target) and non-target (31% of the total non-target) groups. While only 12% of the target group was severely retarded, 31% of the non-target were so classified. Moderately retarded clients were the second most prevalently released in the target group (17%), while 29% of non-target group was in this level of retardation. About 16% of the target group was profoundly retarded, compared to 9% of the non-target group.

## 6.2 Skills of Target and Non-Target Clients Upon Release

Information on the skill levels of released clients from Utah State Training School was collected on the target population only. The percentage of clients possessing various skills upon release from the institution increased from 1972 to 1974, although there was no year in which all target clients released possessed a given skill. The most common skills of these released clients were, according to staff, in the areas of self-help skills, personal hygiene, housekeeping, behavior management, and pre-academic skills. Other skills learned by from one-half to three-quarters of the released target group, as reported by staff, included academics, meal preparation, use of community resources, money management, preparation for job applications and interviews, and specific job skills. Relatively few of the target clients had knowledge of birth control techniques and human sexuality.

### 6.3 Residential and Day Placements of Target and Non-Target Clients

During 1972 through 1974, the most common residential placement for the target population was to natural/adoptive homes (37% of the group). Group homes and independent living situations both received approximately 27% of the total target released group, while cooperative apartments and foster homes each received about 5% of the target group. One interesting comparison which exists within the target group was that while two-thirds of the children and youth released went to group homes, only 10% of the adults in the target group went to group homes. No children were placed in independent living situations whereas 37% of the adults were so placed.

The non-target group's residential placement were less varied than the target group's. Over 80% were placed in nursing homes, 4% of the non-target group went to natural/adoptive homes, 4% to foster homes. Finally, 9% were placed in independent living situations.

Specific information on the day placements for released residents from Utah State Training School was not available for either the target, non-target, or total groupings. Staff at the Training School did indicate, however, that most released residents are involved in a day program which is usually a sheltered work, school or competitive employment situation.

### 6.4 Readmission

Of the target clients released in 1972, approximately 14% were subsequently readmitted to institutional settings. Readmissions increased to 33% for those clients released in 1973, and then decreased again to 20% for those released in 1974. During all three years, readmissions were fairly evenly divided between adults and children. All of the clients readmitted from 1972 releases were male. A slight majority of those readmitted from releases in the next two years were male.

A slight majority of the returnees from all three years had been in the community for six months or less at the time of readmission, although a fairly large percentage of clients released in 1973 and subsequently readmitted had been in the community for six months to one year. The majority of readmissions from all three years returned to the institution from their natural homes. Most of the returnees from all three years had been on extended visit status, although there were readmissions in all three years of clients who had officially been discharged from the institution.

The most common reason for readmission of released clients was parental request. A large percent of the clients were also readmitted due to "community problems", such as jobs not working out, day placements discontinuing, and foster parents leaving the community. Behavior problems constituted the third most frequent reason for readmission, followed by health problems and readmission at the client's own request.

## 7.0 PROFILE OF STUDY GROUP CLIENTS

Of the 133 target clients released from Utah State Training School during 1972 and 1974, 55 or 41% were interviewed between July and August of 1975 and are referred to as the study group (see Glossary). Of these interviewed clients, 4 had subsequently returned to the institution and were interviewed there. In this section, information gathered from institutional staff, records, the study group member, his/her family, housemanager, social worker or other contact person in the community who was interviewed about the study group member will be presented. The information is not intended to serve as a validation of the information gathered from the institution about training, services, or follow-up provided to released clients, nor is it intended to be a "follow-up" of the released clients. Rather, it provides another view of the deinstitutionalization process. The descriptive information will be presented on the types of clients interviewed from Utah State Training School as well as the study groups' perceptions of their problems since release. In addition, information will be presented from the families of the released clients on the institutional follow-up, the types of services received, and the types of services received, and the types of problems encountered since release.

### 7.1 Study Group Characteristics

The age range of the study group released from Utah State Training School was from 8 to 51 years, with an average age of 28 years. Almost two-thirds (63%) of the group was white, about 5% were black, and 8% were American Indian. Almost half of the study group (45%) were mildly retarded, 21% were moderately retarded, and over one-third (34%) were severely retarded. The most common disabilities other than retardation among the study group were speech impediments (45%), mobility limitations (37%), and psychological problems (25%).

## 7.2 Residential and Day Placements

### 7.2.1 Residential Placements

Information was collected on the initial residential placements of the study group upon release and on their current residential settings. The vast majority (90%) of the study group members released between 1972 and 1974 were initially placed in group homes. At the time of the interviews, approximately three-quarters (74%) of the clients were living in such settings. About ten percent of the clients were both initially placed and currently living in natural/adoptive homes. Finally, about 14% were currently living in semi-independent settings and 4% were living independently.

### 7.2.2 Day Placements

Almost two-thirds (61%) of the study group members released from Utah State Training School were initially placed in competitive employment or a sheltered workshop while about a third (32%) were initially placed in a school program. At the time of the interviews, roughly two-thirds of the study group were in competitive employment and about 39% were in a school program. One-quarter of the group was initially placed in a day activity center while current placements showed over a third (35%) so placed. Upon release from the institution, approximately 5% of the study group had no day activity placement while currently, about 10% of the study group was not involved in a day activity.*

## 7.3 Follow-Up

Family respondents were asked if anyone from the institution had follow-up contact with the study group after their release. Over one-quarter (28%) of the respondents reported some follow-up by an institutional staff person. The most frequently reported method of contact was by visitation to the client's home. Other means of follow-up contact were through telephone calls or through contact with a person responsible for the client's welfare.

During the first six months after release, almost one-third (31%) of those followed up were contacted on a monthly basis. During the six-month period prior to the interviews, about a quarter of those followed-up were contacted most frequently on a monthly basis and another quarter most frequently on a twice yearly basis. About 8% reported no contact at all.

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* Multiple day placements were possible so that the percentages exceed 100%.

Family respondents were asked about their satisfaction with the follow-up contact they had received. Almost three-quarters (71%) were satisfied with the follow-up provided while less than a quarter (21%) expressed dissatisfaction with the follow-up provided.

## 7.4 Case Managers

Most of the respondents of the study group (98%) reported that there was a case manager or someone in the community who was responsible for ensuring that the client received appropriate services. During both the first six months after release and the most recent six months, approximately three-quarters (77% and 72% respectively) of the respondents reported that the person serving as a casemanager was a counselor from the community. During the first six months after release, these case managers were in daily contact with about half the study group members and were in weekly contact with the remaining study group members. During the most recent six months, contact with case managers for about half the study group was on a weekly basis and for about half the study group, contact was on a weekly basis.

## 7.5 Services and Training

### 7.5.1 Service and Training Need

Family respondents were asked about the services and training needs of the released study group.* The services cited most often as needed but not received by the study group from Utah State Training School were dental services, occupational therapy, and speech therapy. The types of training cited most often as needed but not received by the study group were reading and writing skills, dealing with emergencies, and using social and community agencies.

Respondents were also asked about their own service needs in caring for the released study group member. The support services cited most frequently as needed but not received were support and/or training prior to the clients' coming to the home (cited by over one-third of the respondents) and on-going family counseling (cited by about one-quarter of the respondents).

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* See Glossary for a list of the support services and training in various skill areas on which information was collected.

### 7.5.2 Service and Training Used

Family respondents were asked about the service and training utilization of the released study group. The study group reportedly used an average of 5 services since their release and received training in an average of 13 skill areas.

Respondents were also asked about the providers of services and training received by Utah's released study group. Of the services used by the clients, respondents reported that almost half (44%) were received from a community agency, while almost a quarter (21%) of the services were provided by Utah State Training School. Community residences reportedly provided 13% of the services, while a similar percentage was provided by the clients' day program. Other community sources were the providers of about 10% of the services used.

Of the training received by the study group, almost half was reportedly provided by the community residences. Almost a third (28%) was provided by the clients' day program and community agencies provided about 19% of the training received. Utah provided about 6% of the training while less than 1% was provided by other community sources.

## 7.6 Problems Encountered by the Study Group Since Release

Family respondents were asked about a series of problems which may have been experienced by the study group since their release. Respondents were also asked about the severity of these problems. Family relationships were the most frequently mentioned problem of the greatest severity for the study group. Other problems mentioned included behavior problems, medical problems, and loneliness.

The study group was also asked about their perceptions of the problems they have had since release. The most frequently stated problems were budgeting money, handling family relationships, loneliness, and developing self-confidence.

Of the released study group, 4 clients subsequently returned to Utah State Training School. Respondents for these clients were asked about the reasons for the clients' return. The most frequently stated reasons were due to behavior problems, illness, and difficulties in keeping a job in the community.

## 7.7 Adjustment

Following each interview session, interviewers were asked to record their impressions of the study group's adjustment to the community along three dimensions: degree of social isolation, degree of satisfaction or happiness with their life in the community, and overall degree of adjustment to the community. These measures are subjective in nature yet provide another perspective to the community adjustment of the released study group.

Almost two-thirds (63%) of the study group members were perceived by the interviewers to have social relationships with others. Approximately 18% of the clients seemed socially isolated. The interviewers were unable to judge the social isolation of 20% of the study group members.

The interviewers perceived two-thirds of the study group members as satisfied with their current life in the community. Approximately 6% of the clients appeared somewhat dissatisfied and for about a quarter of the group (28%), the interviewers were unable to describe the client's degree of satisfaction or happiness in the community.

About three-quarters of the group were perceived to be adjusting well overall to the community. Only 7% were perceived to be poorly adjusted. The interviewers were unable to judge the overall adjustment to the community for 18% of the study group.

# CHAPTER 12.0: YORKTOWN STATE SCHOOL

## 1.0 INTRODUCTION

### 1.1 Overview

The Yorktown State School is the only public institution for mentally retarded persons serving a midwestern state.* For the past nine years, the institution has been actively involved in placing people into a variety of community settings. Recent court actions may require that Yorktown make further sharp reductions in its population, hopefully, becoming more integrated into the continum of services available throughout the communities of the state. The state has a well developed network of community support services for mentally retarded people funded through the federal, state, and county governments.

Yorktown State School's overall client population has declined in recent years from 1,380 residents in 1972 to 1,189 residents in 1974, constituting a 14% reduction. The 1975 population of 1,017 residents represents an additional 14% reduction. Females comprised around 43% of the total population during each of the years under study. The age range of the residents at Yorktown has shifted during this period, however. In 1972, 62% of the clients were aged 18 and under. In 1973, the children and youth population served by Yorktown was 56% of the total population, while in 1974, 51% of the population was aged 18 or under. Currently, 40% of the institution's total client population is 18 or under.

The distribution of residents according to level of retardation has shown distinct changes in the mildly retarded and profoundly retarded populations. During the 1972-1974 period under study, the proportion of mildly retarded residents went from 13% of the total population in 1972 to 8% in 1974. By 1975, only 4% of the institution's population was classified as mildly retarded. While the number of mildly retarded clients has declined, the number of profoundly retarded residents has increased. In 1972, 7% of the total institutional client population was profoundly retarded, while in 1974, 15% of the total population was profoundly retarded. Currently, 34% of the population is profoundly retarded. Moderately retarded clients constituted about 23% of the population for the 1972-1974 period while of the current institutional population, 17% are moderately retarded. Severely retarded clients constituted about 56% of the population during 1972-1974. During 1975, this group has dropped to 44% of the total population.

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*The Yorktown State School is a fictionalized name.

The incidence of other handicapping conditions in addition to mental retardation remained substantially the same except for two categories during the period under study and currently. There was a marked increase in the incidence of visual defects. In 1972, 6% of the population had visual defects; by 1974, 14% of the population had visual defects and 1975 figures showed 17% of the population with visual defects. In addition, the number of clients with mobility problems or limitation declined in recent years. In 1972, 45% of the population had mobility problems, while in 1974, the figure was 31%. In 1975, however, only 19% of the population had mobility problems.

Residents of Yorktown State School, are, by the vast majority, court committed. In the 1972-1974 period, about 82% of the residents were admitted by court action. The current population is 77% court committed. The number of residents admitted by family or guardian authorization remained consistently around 15% for the period under study.

Per capita expenditures at Yorktown steadily increased during recent years. The average per capita expenditure was $5,443 in 1972. In 1973. the figure rose to $6,447, while the following year, the figure was $9,262, representing a 41% increase from the 1972 expenditure level. 1975 per capita expenditure figures were unavailable.

The staff at Yorktown State School experienced an overall increase of 7% between 1972-1974 from 1,001 staff in 1972 to 1,075 staff members in 1974. These increases occurred primarily in the therapist (other than counselors), rehabilitation/vocational counselor, and psychologist positions. For example, in 1972, there were about 38 therapists, or about 4% of the staff for that year. By 1974, the number of therapists had reached 100 or about 9% of the 1,075 persons employed at the institution that year. Vocational/rehabilitation counselors more than doubled in number during the period under study, from 8 in 1972 to 19 in 1974. Finally, there were 17 psychologists in 1972 as compared to 32 in 1974. The most substantial decrease in staff occurred in the attendant position, from 52% of the staff in 1972 to 43% of the staff in 1974. Other staff categories have maintained their general proportional distributions over the period under study, with slight increases in the administrative and medical technician staff categories. Staff increases between 1974 and 1975 were primarily in the psychologist, therapist and support staff positions. There was an overall increase from 1,075 staff in 1975 to 1,199 in 1975.

Yorktown State School is in the process of making the necessary adjustments to meet accreditation standards at the present time.

## 1.2 State Context

### 1.2.1 State's and Institution's Deinstitutionalization Policies

Since 1967, the general philosophy of the State Department of Mental Health has been to place a client out of the institution when the receiving program is as good or better, and closer to home, than the institution. This philosophy is consistent with state legislation addressing this topic. (See Section 1.3)

The Yorktown State School sets goals for the number of clients to be released each year. These goals are based on funding expected for community programs, and comparability of community programs with those operating in the institution. For example, if the institution is aware that there is a community program employing mentally retarded persons to do assembly work, and if similar assembly work is being done (or taught) at Yorktown, then the institution will adjust its goals according to the number of places which might become open in the community program for Yorktown residents. Goals for number of clients to be released stayed constant from 1972-1974 at around 11% of the institution's population, and therefore, the absolute numbers of clients to be released declined from 200 in 1972, to 150 in 1974 as the total population of the institution declined.

## 1.3 State Legislation Relating to Deinstitutionalization

### 1.3.1 The Right to Education Law and Its Impacts

In 1973, the state passed two laws relating to children with handicaps; school systems were required to be in full compliance with both laws by 1976, but full implementation was achieved at Yorktown during the 1974-1975 academic year. The first law mandates education for children with special needs, and covers students between the ages of 5 and 18 years. The second law specifically concerns multiple handicapped children between 5 and 21 years of age. As a result of this legislation, students with all handicapping conditions, at all levels of severity, are entitled to appropriate public education services. However, the laws are too recent to have had any clear-cut impact on the institution's programs and procedures as yet.

### 1.3.2 The Periodic Review Law and Its Impacts

Although the state has not passed any periodic review legislation, the Yorktown State School has an administrative policy which requires that residents be periodically assessed. Established in early 1975, the policy states that residents will be reviewed by a multi-disciplinary team each year, by birth date. From 1972 to 1974, clients were assessed by a multi-disciplinary team every three years. Like the right to education laws, the periodic review policy is too recent to have any clear-cut impact on Yorktown's programs and procedures.

## 1.4 State Litigation Relating to Deinstitutionalization and Its Impact

During the 1972-1974 period, the state has been involved in a continuing class action suit relating to the question of whether or not a client has a right to live in the least restrictive environment possible. The original plaintiffs in the suit were the parents of five Yorktown clients, who worked through the State Association for Retarded Citizens. Later on, the U.S. Justice Department, and representatives from a law school in another state, became the plaintiffs. The case has not yet been settled.

According to Yorktown administrators, the litigation has encouraged parents of clients to join the national, state and local Association for Retarded Citizens, and has to some extent polarized parental attitudes on the subject of what constitutes the least restrictive environment for Yorktown clients.

## 2.0 CLIENT ASSESSMENT PROCEDURES

Upon admission, each client at Yorktown is formally evaluated by a multi-disciplinary team. Clients are then assigned to units within the institution. Clients released during 1972-1974 were assessed by the multidisciplinary team in each unit at least every three years. In general, for all three years, psychological and social assessments occurred once every two years, medical and vocational assessments occurred annually, and educational assessments occurred twice per year.

For all three years, the following staff were involved in client assessments: the unit coordinator, psychologist, social worker, nurse, vocational rehabilitation counselor, and direct care staff. In 1973 and 1974, educators also participated in assessments, and in 1974 a speech therapist was added to each assessment team.

During 1972, 1973 and 1974, released clients did not review or discuss their assessment results with staff, although there are plans to include client input to the assessment process in the future. Clients may have input into the decision-making process regarding future placement to the extent that they may visit their prospective placements and then discuss them with staff. Clients also discuss placements with either the institution social worker or the community social worker.

In the three-year period, families, guardians, and advocates of released clients were not generally invited to participate in regular assessments. Although social workers from the Regional Offices of Mental Retardation and representatives from the County Welfare Office and Vocational Rehabilitation were generally invited to participate in regular assessments of target clients, they generally did not attend.

## 3.0 PRE-RELEASE PROGRAMS

### 3.1 Introduction and Program Description

The Yorktown State School has a full sequence of developmental programs for its residents regardless of their age or level of handicap. Each client has an individualized plan which specifies his/her developmental needs and establishes future goals. As a result of this individualization in programming, Yorktown does not have institution-wide pre-release programs. The staff feel that all their programs are designed to help prepare the individual resident to move into community settings.

All target clients released from the institution during 1972-1974 received training in self-help skills and personal hygience, and most had pre-academic skills. Over half were trained in specific job skills, and half had training in housekeeping. A smaller number of clients had been involved in behavior management programs, aimed at eliminating inappropriate behaviors. Small numbers of clients also received training in meal preparation, academic skills, use of community resources, use of public transportation, money management, preparation for job applications and interviews, and birth control techniques.

### 3.2 Overall Characteristics of Pre-Release Programs

The staff at Yorktown feel that the primary strength of their program lies in the individualization of client programs, so that each client is trained along a developmental sequence according to her/his individual needs. They feel, however, that clients at the institution have limited exposure to community experiences. There is very little tie-in with community-based programs, and the admission criteria are difficult to assess. Program staff at the State School have made attempts to include more exposure to community life in their programs. Also, in conjunction with the Regional Offices of Mental Retardation, Yorktown requests updated information on admission and release criteria of community programs in each region of the state.

## 4.0 RELEASE PROCEDURES

### 4.1 Key Staff and Major Steps Involved

The placement process remained the same from 1972 through 1974. As stated earlier, each client was evaluated by a multi-disciplinary team at least every three years. This assessment delineated the specific needs of individual clients. The results of the assessment were compiled and sent to the Regional Office of Mental Retardation closest to the client's home. The process was effected through the institutional social worker, who served as a liaison between the State School and the Office of Mental Retardation.

When the regional social worker became aware of openings in appropriate settings, s/he alerted the institutional liaison social worker. The institution then reassessed all clients who might fit the criteria for entry into the program. Those clients meeting the specified criteria were screened by the Community Regional Office of Mental Retardation liaison social worker and others, as needed (e.g., houseparents or teachers). Those people had access to clients' records and also consulted with institution staff concerning the screening.

If an appropriate match existed, the State School and Office of Mental Retardation social workers decided who would contact the client's family. The client then visited the prospective setting and discussed his/her feelings concerning the placement with the institution liaison social worker. An Office of Mental Retardation community caseworker then made all financial and other arrangements, and the placement was effected.

This procedure was followed whenever a client was placed in a setting other than his/her parents' home, regardless of whether the placement was institution- or family-initiated. If the client was to be placed in his/her natural home, and would be attending a private educational facility after return to the home, liaison social workers were not always involved. However, the institution always notified the Regional Office of Mental Retardation of any placement.

The most important criterion in determining client placement across all three years was the availability of a residential setting in the community. The determination as to which client was to be placed in the residential setting was dependent on various clients' functional levels and a variety of other criteria such as medical situation, availability of appropriate services in a particular community and availability of training in the community.

### 4.2 Factors Affecting Release

According to staff at the institution, clients easiest to place include those with high social skills and few, if any, behavior problems. Clients are also felt to be easier to place if they have no medical and/or orthopedic problems, and if they have potential for semi-independent living.

Clients felt to be most difficult to place include those with serious emotional and/or behavioral problems, such as aggressiveness, inability to accept routines, tendency toward open masturbation, and so on. Deaf clients are seen to be particularly difficult to place, as are clients with medical problems, and those who are non-ambulatory.

### 4.3 Client Status Upon Release

Across all three years, the large majority of clients released were institution-initiated, and most releases were on extended visit trial status. During 1972 and 1973, a client placed in the community on extended visit status could retain that status indefinitely. During 1974, a client released on extended visit status could retain that status for six months, with a possibility of a six-month extension by the Office of Mental Retardation.

The fact that an individual resides at Yorktown State School does not affect her/his legal powers to marry, vote, enter into an employment contract, or secure legal services. However, a resident may not voluntarily leave the facility, or refuse services offered by the State School, with the exception of elective medical treatment (e.g., cosmetic surgery). These restrictions are lifted when a client is placed into the community.

## 5.0 FOLLOW-UP PROCEDURES AND SUPPORT SERVICES FOR RELEASED CLIENTS

### 5.1 Follow-Up Procedures

The institution does not provide any follow-up services for clients released into the community. All follow-up is handled by social service staff of the Regional Offices of Retardation. Social workers from that agency follow up all clients at least once a month. The client's placement and individual needs are reviewed every six months, and modifications are made if necessary.

### 5.2 Support Services Provided to Clients

#### 5.2.1 Agencies with Continuing Responsibilility for Client's Welfare

When a client is released to a community setting, either on extended visit or discharge status, the Regional Office of Mental Retardation has primary continuing responsibility for ensuring the client's well-being. Individuals do, however, have the right to return voluntarily to Yorktown without regard to waiting lists or waiting periods. Moreover, the Superintendent of Yorktown has the legal power to return clients released on extended visit status to the institution, although s/he cannot change the client's placement within the community from one setting to another.

#### 5.2.2 Types of Support Services Provided to Clients

Follow-up support services available to clients through the Regional Office of Mental Retardation include social services, medical care, and educational, vocational, and recreational programs. All clients released in 1972, 1973, and 1974 received social and medical services, and participated in recreational services. Over half received vocational training, and approximately one-fourth participated in educational programs. Frequency of specific follow-up is determined every six months during the program review for each client. All support services provided to clients were perceived to be adequate, in regard to both quantity and quality, according to Yorktown staff.

### 5.3 Support Services Provided to Those Responsible for Released Clients

The Yorktwon State School provides no training to the families of clients in order to prepare those families to work with clients. However, in 1972, 1973, and 1974, the institution did provide training to teachers and employers of released clients in order to facilitate client placements. Instruction was given in the areas of behavior management, manual communication for the deaf, and operant conditioning techniques.

### 5.4 Institution's Assessment of Released Clients' Admustment to Community Living

Given that the Regional Office of Mental Retardation has primary responsibility for the placement and follow-up of Yorktown's released residents, the institution does not have assessment measures for clients' adjustment to community life.

## 6.0 RELEASED CLIENT PROFILE

As stated earlier in Section 1.0 , released clients were categorized in two groups: target and non-target releases (see Glossary). In this section, information will be presented on the entire deinstitutionalized population of 1972-1974 and then information will be presented on the target and non-target client releases. Since the focus of the study was on the target clients released, more information is reported on this group than on the non-target clients released.

As stated earlier, Yorktown State School set a goal that 11% of its population be released each year to community settings. During the 1972-1974 period under study, the actual release rates varied from 14.4% in 1972, to 10% in 1973 and 1974. This represents a total of 448 mentally retarded people released over the three year period. The largest group of 200 people were released in 1972. In 1973, 128 clients were released while in 1974, 120 clients were placed in community settings of other facilities.

Of these 448 released clients, the slight majority were males. 13% were between the ages of 6 and 18 and 87% were adults, aged 19 and over. Mildly retarded clients comprised 31% of the total releases for these years. 25% of the released group was moderately retarded, 27% severely retarded, and 3% were considered profoundly retarded. The most frequent additional handicaps other than mental retardation were epilepsy, mobility limitations, and visual impairment.

The most frequent residential placement was to group homes where 71% of the released clients were placed. The next most frequent setting to which 18% of the population was placed was to nursing homes or other institutional settings. Natural/adoptive homes received 7% of the total released population. Only 2% were released to independently living settings; 1% to foster homes; none to semi-independent settings.

## 6.1 Characteristics of Target and Non-Target Clients

Of the 448 released clients, 56% or 252 were target clients as defined in the Glossary. 112 target clients were released in 1972, 38 target clients were released in 1973, and 82 target clients were released in 1974. These target clients constituted 8% of the total institutional population in 1972, 5% of the total population for 1973, and 7% of the total population in 1974. Non-target releases numbered 88 in 1972, 70 in 1973, and 38 in 1974 for a total of 196 non-target client releases. The majority of both target and non-target clients were adults, aged 19 through 40 years. In 1973 and 1974, target client releases between males and females were fairly evenly divided while in 1972, the slight majority were males. Of the non-target released clients, males constituted about 59% of the releases over all three years.

The level of retardation of released target clients, 35% were mildly retarded, 31% were moderately retarded, 32% were severely retarded, and 1% profoundly retarded. Among the non-target releases, 37% were mildly retarded, 24% were moderately retarded, 31% severely retarded, and 8% were profoundly retarded.

In 1972 and 1973, the primary handicap other than retardation of target clients released was epilepsy; approximately 20% of the clients released in those years and in 1974 were epileptic. In 1974, over one-third of the target clients released had visual problems ranging from correctable visual difficulty through total blindness. Mobility limitations were another frequent additional handicap to target as well as non-target clients. Epilepsy and visual difficulties were common handicaps among the non-target clients as well.

For all three years, the large majority of clients released from Yorktown had originally been placed in the institution through the court system. A relatively small percent were admitted as a result of authorization by a parent or guardian or as a result of transfer from another institution.

## 6.2 Skills of Target and Non-Target Clients Upon Release

According to staff, the types of skills in which training was given did not vary between 1972 and 1974. A large majority of clients released in all three years possessed skills in self-help, personal hygiene, and did not have behavioral problems. A good many also had some pre-academic skills. Approximately half of those released across all three years also had skills in housekeeping, preparation for job applications and interviews, and specific job-related areas. A relatively small percentage of those released in the three-year period possessed skills in meal preparation, birth control techniques, money management, use of community resources, and use of public transporation; few possessed such academic skills as reading, writing, and math.

### 6.3 Residential and Day Placements of Target and Non-Target Clients

Eighty-five percent of the target and 56% of the non-target clients from Yorktown during the 1972-1974 period were released to group homes. The second most frequent type of placement for target clients was to natural or adoptive settings (10%). Four percent of the non-target clients were released to natural/adoptive homes. Very few target clients were placed in other settings during the three-year period. Approximately 25% of the target clients released had visited their future residential settings within the six months prior to their release.

Non-target clients differed in residential placements from the target clients in one significant aspect. Thirty-five percent of the non-target clients were placed in nursing homes and 5% to other institutional settings. It should again be noted that one of the criteria for the target population was that the community setting into which they were placed not be a nursing home or other facility serving 100 or more clients. Therefore, the high percentage of non-target clients being placed in these types of settings was not unexpected.

Over half of the target clients released from the institution from 1972-1974 went to workshop placements. Most of the remaining day placements were special state-funded day programs. A relatively small number of target clients went into competitive employment settings. Across all three years, 15% of the target clients visited their day placements prior to release from Yorktown. Information on the day placements of non-target clients released from Yorktown was not obtained.

## 6.4 Readmissions

The percent of target clients readmitted to Yorktown who had been released in 1972, 1973, or 1974 was very small, ranging from 8% of those released in 1972 to 1% of those released in 1974. One-third of those readmitted from 1972 released were children, and two-thirds were adults. These figures were reversed for those target clients readmitted who had been released in 1973. Of those clients who had been released in 1974, 100% readmitted were adults. Two-thirds of the readmitted clients from 1972 and 1973 were male; all of those from 1974 were female.

The majority of target clients readmitted from all three years returned to the institution from group homes, although a fair number of those returning from 1972 and 1973 releases had originally been placed in foster homes. The larger majority returned after less than six months in the community. Most readmissions were due to inappropriate behavior such as aggressiveness; other primary or precipitating reasons for readmission included failure to adjust to group home life, regression, and parental request.

Readmission information for non-target clients released from Yorktown was not obtained.

## 7.0 PROFILE OF STUDY GROUP CLIENTS

Of the 252 target clients released from Yorktown State School between 1972 and 1974, 103 or 41% were interviewed during July and August of 1975 and are referred to as the study group (see Glossary). Of these 103 interviewed clients, 13 or 13% had subsequently returned to the institution and were interviewed there. In this section, information gathered from institutional staff, records, the study group member, his/her family, housemanager, social worker, or other contact person in the community who was interviewed about the study group member will be presented. The information is not intended to serve as a validation of the information gathered from the institution about training, services, or follow-up provided to released clients, nor is it intended to be a "follow-up" of the released clients. Rather, it provides another view of the deinstitutionalization process. The descriptive information will be presented on the types of clients interviewed from Yorktown State School, as well as the study group's perceptions of their problems since release. In addition, information will be presented from the families of the released clients on the institutional follow-up, the types of services received, and the types of problems encountered since release.

### 7.1 Study Group Characteristics

The age range of the study group release from Yorktown State School was from 7 to 49 years, with an average age of 26 years. Over three-quarters of the group were white, 14% were black, and 2% were American Indian. Over one-third of the study group (37%) were mildly retarded, 30% were moderately retarded, approximately one-quarter (26%) were severely retarded, and 3% were profoundly retarded. The most common disabilities other than retardation among the study group were speech impediments (47%), mobility limitations (21%), and epilepsy (21%).

## 7.2 Residential and Day Placements

### 7.2.1 Residential Placements

Information was collected on the initial residential placements of the study group upon release and on their current residential settings. The vast majority (80%) of the study group members released between 1972 and 1974 were initially placed in group homes, while at the time of the interview, 59% of the clients were living in such settings. About 10% of the clients were initially placed in natural/adoptive homes, and at the time of the interview, 13% were in such settings. Foster homes, the initial placement for 2% of the study group, had only 1% of the group at the time of the interviews. Finally, although only 1% of the study group members were initially placed in independent homes, 15% were living in such a setting at the time of the interviews.

### 7.2.2 Day Placements

Study group members released from Yorktown State School were most frequently placed initally in competitive employment or sheltered workshops (54%), or in a school program (31%). Approximately 28% of the group were initally placed in a day activity center. Three clients (3%) initially were not placed in any day program.

At the time of the interviews, however, about two-thirds (65%) of the study group members were in a competitive employment situation or a sheltered workshop. Almost half (43%) were involved in a school program, and over one-third (36%) attended a day activity center. Approximately 6% of the study group had no day activity.* Reasons cited most frequently by respondents for the absence of a day activity were that there were no appropriate programs or jobs available in the community or that everyone was having difficulty obtaining a job in that area.

## 7.3 Follow-Up

Family respondents were asked if anyone from the institution had follow-up contact with the study group after their release. About 41% of the respondents reported some follow-up by an institutional staff person.

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* Multiple day placements were possible so that the percentages exceed 100%.

The most frequently reported method of contact was by visitation to the client's home. Other means of follow-up were contact with a person responsible for the client's welfare (such as the social worker), visitation to the client's day placement, or by telephone.

During the first six months after release, over a third (39%) of the study group were reportedly followed up about once a month. During the six-month period prior to the interview, less than one-third (29%) of the respondents reported similar follow-up frequency, and 6% reported no contact at all.

Family respondents were asked about their satisfaction with the follow-up contact they had received. Almost two-thirds (62%) reportedly were satisfied with the follow-up provided, while approximately 11% reported dissatisfaction with the follow-up provided. About a quarter reportedly were neither satisfied nor dissatisfied.

## 7.4 Case Managers

Most of the respondents of the study group (98%) reported that there was a case manager or someone in the community who was responsible for ensuring that the client received appropriate services. During both the first six months after release and the most recent six months, two-thirds of the respondents reported that the person serving as a casemanager most often was a counselor from the community. During the first six months after release, these case managers were in daily contact with over half (60%) the study group members. During the most recent six months, client contact occurred on a weekly basis for almost half (48%) of the study group members.

## 7.5 Services and Training

### 7.5.1 Service and Training Needs

Family respondents were asked about the services and training needs of the released study group.* The services cited most often as needed but not received by the study group from Yorktown State School were speech therapy, dental services, and camp facilities. The types of training cited most often as needed but not received by the study group were reading and

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* See Glossary for a list of the support services and training in various skill areas on which information was collected.

and writing, vocational training, language skills, dealing with emergencies, and using social and community agencies.

Respondents were also asked about their own service needs in caring for the released study group member. The support services most frequently cited as needed but not received prior to the client's coming to the residence (mentioned by almost one-half of the respondents) were respite care or relief from responsibilities and parent or professional associations.

### 7.5.2 Service and Training Used

Family respondents were asked about the service and training utilization of the released study group. The study group reportedly used an average of 5 services since their release and received training in an average of 14 skill areas.

Respondents were also asked about the providers of services and training received by Yorktown's released study group. Of the services used by the clients, respondents reported that over half (54%) were received in a community agency, while 14% were received from the community residence where the client was living, and 10% were received from the client's day programs. The institution reportedly provided 5% of these services, and other community sources were reported as providing 16% of the services used.

Of the training received by the study group, almost half (49%) was provided by the community residences. Almost a third (29%) of the training was reportedly provided by the clients' day programs, and community agencies were reported as providing nearly a quarter (21%) of the training received. Both the institution and other community sources provided less than 1% of the training received by the study group.

## 7.6 Problems Encountered by the Study Group Since Release

Family respondents were asked a series of questions regarding the types of and degree of problems which may have been experienced by the study group since their release. Family relationships were the most frequently mentioned problem of the greatest severity for the study group. Other problems cited by the respondents included keeping a job, loneliness, and behavior problems.

The study group was also asked about their perceptions of the problems they have had since release. The majority of clients said that the most difficult was budgeting money. Other difficulties cited were finding a job, social relationships, psychological problems, and loneliness.

Of the released study group, 13 clients subsequently returned to the institution and were living there at the time of the interviews. Respondents for these clients were asked about the reasons for the clients' return. The most frequently stated reasons were due to court commitment or that the client did not get along with the people in his or her residence.

### 7.7 Adjustment

Following each interview session, interviewers were asked to record their impressions of the study group's adjustment to the community along three dimensions: degree of social isolation, degree of satisfaction or happiness with their life in the community, and overall degree of adjustment to the community. These measures are subjective in nature, yet provide another perspective to the community adjustment of the released study group.

The vast majority (86%) of the study group members were perceived by the interviewer to have social relationships with other persons. Only 9% of the clients were perceived to be socially isolated from those around them. The interviewer was unable to judge the social isolation of 6% of the clients.

Nearly all (85%) of the study group members appeared to the interviewer as satisfied with their current life. Approximately 7% of the clients appeared somewhat dissatisfied. The interviewer was unable to judge the client's satisfaction in 9% of the cases.

The majority of the study group members (88%) appeared to be well adjusted to living in the community. Only 5% were perceived to be poorly adjusted. The interviewers were unable to determine the adjustment or maladjustment in 8% of the cases.

# GLOSSARY

Additional Handicapping Conditions: These refer to handicaps other than mental retardation, including visual or auditory impairments, mobility limitations, psychiatric problems, or epilepsy.

Age Group: Target clients were grouped into two age categories: ages 18 and under were considered children and youth, while adults were those clients between the ages of 19 and 40 years.

Casemanager: This term refers to anyone in the community who is responsible on an on-going basis for ensuring that a person receives appropriate services and support.

Client Assessment Procedures: Steps used by the institution to assess or review the needs and progress of residents while living in the institution. Includes both the formal psychological and educational testing and informal judgments by staff.

Community: This refers to the setting in which the individual is placed when released from the institution. "Community" must be viewed broadly and includes the following contexts: individual's place of residence, place of work, and places of social activity. This includes, as well, the immediate neighborhood and the larger surrounding community.

Community Adjustment: This study assumes that community adjustment is a two-way process: 1) the process of the individual adapting to the demands and requirements of daily living in a community as opposed to an institutional setting; and, 2) the process of the community adapting to the demands and needs of the individual. The adaptive behaviors necessary for community living which this study examines include measures of personal, vocational, social and civic adjustment. This study also assumes that there are no rigid criteria for defining "successful" or "unsuccessful" community adjustment. Rather, the concept of adjustment is relative to the context of the community setting in which the individual is living (including the individual's residential, work and social settings). Ideally, in order to get a total picture of the community adjustment process, the adaptive behaviors of the individual to these contexts must be studied as well as these settings' adaptation to and acceptance of the individual.

Community Placement: May include natural homes, foster homes, cooperative apartments, group homes, as well as independent living units. However, in this study, community placements do not include residential settings which are as restrictive or as sheltered as the institutions from which clients were released (e.g., nursing homes, state schools, and state hospitals) nor are any residential settings serving over 100 persons considered a community placement.

Deinstitutionalization: In its most limited and narrow sense, deinstitutionalization refers to a planned reduction in the number of persons residing in institutions for the mentally retarded. However, for the purposes of this study, a broader definition has been utilized.

Deinstitutionalization in this study, refers to the process of placing mentally retarded persons from institutions into community based settings (see definition of community placement). This process includes the following interrelated activities: 1) the on-going assessment of clients in institutions to determine their readiness and appropriateness for community placement; 2) the preparation and training of clients at the institution in skills necessary for eventual community placement; 3) the procedures undertaken by the institution to secure and/or develop community placements for residents; 4) the follow-up efforts on the part of the institution to monitor the progress of residents in their community placements and to provide any assistance to facilitate the community adjustment of former residents. This study focuses on deinstitutionalized clients between the ages of 6 and 40 who have been placed in community-based residences following their enrollment in residential institutions (facilities serving over 100 handicapped clients) for two years or more.

Discharged: A mentally retarded person is considered to have been discharged if s/he is no longer officially on the rolls of the institution. Some institutions automatically discharge residents when they are placed in the community; others place residents in the community on a trial basis before formally discharging them (see "Extended Visit").

Extended Visit: A mentally retarded person is considered to be on extended visit status if s/he is living outside the institution but is still officially counted on the rolls and is considered to be part of the institution's clientele. Other terms used by institutions to indicate an extended visit status include "temporary discharge" or "trial leave." The exact minimum and maximum lengths of extended visits involved are likely to vary from institution to institution. This status is often the first one used when a person is initially placed in the community on a trial basis from the institution until reasonable assurance of successful community adjustment has been obtained.

Follow-Up: Any effort made on the part of the institution to keep track of where former residents are living, and how well they are doing in their new placements, including direct contact with the released resident or contact made with responsible social workers, employers, or residential staff of the released resident is considered to be follow-up.

Follow-Up Support: Any assistance which an individual mentally retarded person receives which facilitates his/her adjustment to community placement. Follow-up support services are typically received through a resident's social worker or through institutional services available for released clients.

Institution: Any environment which provides a "total care" system for handicapped clients within its physical boundaries. Most, and in many cases, all human services including shelter, food, medical care, recreation, habilitative and/or educational services, etc., are provided for clients on the institution's grounds. For the purposes of this study, a facility had to serve over 100 residents in order to be considered an institution.

Institutional Control: This term refers to whether the institution is privately owned and controlled, or whether it is a publicly operated facility.

Institutional Staff: Information was collected on the number of staff employed at the institutions for the following positions: administrators, medical doctors, psychiatrist, psychologist, social workers, therapists, rehabilitation/vocational counselor, nurse, attendant, teacher, support staff, other staff.

Levels of Retardation: The levels of retardation used in this study are mildly retarded (IQ 68-72), moderately retarded (IQ 51-36), severely retarded (IQ 35-20), and profoundly retarded (IQ 19 and below). These are the levels and definitions used by the American Association on Mental Deficiency (AAMD). Mild retardation is roughly equivalent to the educational term "educable;" moderate retardation includes those individuals who are likely to fall into the educational category of "trainable;" the severe group includes individuals sometimes known as "dependent retarded;" individuals in the profound retardation level are among those sometimes called "life support" level.

Non-Returnees: Members of the study group interviewed while they were living in the community. They were the people who had remained in the community since their release from the institution, or who, if they had returned to the institution, had been released again.

Non-Target Clients: Non-target clients are all clients released from an institution between 1972-1974 who do not meet the criteria specified for inclusion in this study (i.e., they can be less than 6 years or more than 40 years old, have been in the institution for less than 2 years prior to release, and/or have been placed in non-"community" settings such as nursing homes, state hospitals, etc.). (See below.)

Overall Releases: This refers to the total number of clients released from the responding institutions between January 1, 1972 and December 31, 1974 who were between the ages of 6 and 40 years at the time of their release and who had resided at the facility for at least two years prior to their release. The type of placement to which the client was released was not specified for this count and thus, the overall release number includes both target and non-target clients.

Periodic Review: This is a procedure, often mandated by state legislation, through which residents in institutions (or other state programs) are evaluated on a regular basis. The objective of this review is usually to determine the appropriateness of the current programming for a client and to provide the basis for revised programming if appropriate. Thus, periodic review is often performed by an interdisciplinary team which examines a broad range of capabilities and achievements in an individual client. The state legislation usually prescribes the frequency of the periodic review (e.g., at least once a year) as well as the nature of the review (e.g., it must include a psychological review, an intelligence test, etc.) and even the participants in the review (the professionals to be involved and the role of parents). New York, Pennsylvania, and Massachusetts are some of the states which have passed such laws.

Post-Release Services: Many institutions provide continuing support for released residents. These support services may include medical and dental care, social services and counseling, and/or respite care.

Pre-Release Program: Many institutions have developed special programs which are specifically designed to prepare clients for placement into community settings. These programs provide training in various skills considered necessary for living in the community. The programs include separate residential facilities on the institution's grounds which are developed to prepare residents for the demands of community living, sheltered workshops, competitive work placement, and schools either within the institution or the community. Typically, different programs exist for children and for adults. A few institutions consider all their efforts to constitute "pre-release" programming.

Region: Institutions responding to the Institutional Mail Questionnaire were grouped into four geographic regions as follows:

Northeast: Connecticut, Delaware, Maine, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Pennsylvania, Vermont.

North Central: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin.

South: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia.

West: Arizona, California, Colorado, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, Wyoming.

The institutions in the states of Alaska and Hawaii were not included in the Institutional Mail Questionnaire.

Released: A person is considered released from the institution when s/he has been placed in the community either on a formal discharge or extended visit status (see definitions of these terms in the Glossary). A person is not considered released when the placement is only for a short period of time (e.g., a week's leave) and when return to the institution is expected or required.

Release Procedure: This refers to either the formal or informal process established within an institution for the selection of and eventual release of an institutional resident.

Returnees: Those members of the target group of released clients who had returned to the institution. The term is used in this project to refer to those individuals who were back at the institution when the interviews were conducted.

Right to Education Law: This refers to state legislation which provides for the education and training of handicapped children within the public school system. Generally, right to education laws mandate that all children (regardless of level of retardation or level of handicap) have the right to a public education--either in a special education class or in a regular classroom program. In some states, the law applies to children from 0-21 years. In other states, the age range may be more limited.

Study Group: This refers to those target clients who were contacted with the assistance of the institutions for Abt Associates and subsequently agreed to participate in the study. Study group members, therefore, are a self-selected sample of the released target group.

Study Group Respondents: The term "respondent" refers to the study group's contact person interviewed in the community about the study group member's experiences since release. Respondents were, in general, a natural/adoptive parent, a foster parent, a group home manager, or a social worker. The respondents gave information on the institutional follow-up provided, on the existence of a casemanager, on the study group member's residential and day activities history, on the types of services and training received since release, and on the types of problems encountered by the study group.

Support Services for Clients: Interviewed study group respondents were asked about twelve types of support services which may have been available in the community. These support services on which information was collected were: medical services, dental services, social/psychological counseling, job counseling and/or evaluation, camp, recreational/social programs, occupational therapy, speech therapy, physical therapy, legal assistance, housing assistance, and other support service.

Support Services for Families: Study group respondents were asked about six types of support services which may have been available to them in the community. These services on which information was collected were: support and/or training prior to client's coming to the residence, on-going counseling for the family, consultation for handling specific problems, respite or relief from responsibilities, parent or professional associations, and other services used or needed.

Target Clients: Target clients refer to those mentally retarded persons between the ages of 6 to 40 years who were released between 1972 and 1974 into a community setting other than a nursing home or residential facility serving 100 or more persons after having resided at an institution for at least 2 years prior to their release. Released clients who meet this definition constitute the primary group of deinstitutionalized clients selected for study in this project. The distinction made between target and non-target clients is solely a function of this study and does not indicate a distinction made by institutions or institutional personnel.

Training: Interviewed study group respondents were asked about 24 skill areas in which the released group may have received training since their release. These training areas were: eating (self-feeding and table manners), toilet use, cleanliness (washing, personal hygiene), dressing and undressing, personal appearance (posture, neatness of dress), motor skills, sensory (hearing and vision), language (speech, comprehension), pre-academic skills (shapes, colors, sizes), numbers and telling time, reading and writing, prevocational skills, vocational training, housekeeping, meal preparation, traveling skills, using a telephone, money management, shopping skills, dealing with emergencies, using social and community agencies, interpersonal relationships, behavior management, and recreation skills.